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Protecting and improving the nation's health

Hepatitis C in the North East

2017 data

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Glossary of abbreviations

Anti-HCV	Antibodies to hepatitis C virus
BBV	Blood borne virus
DAA	Direct-acting antiviral agent
DAT	Drug action team
DBS	Dried blood spot
DSR	Directly standardised rate
ESLD	End-stage liver disease
GUM	Genitourinary medicine
HCC	Hepatocellular carcinoma
HCV	Hepatitis C virus
HES	Hospital episode statistics
HIV	Human immunodeficiency virus
HMP	Her Majesty's Prison
HMYOI	Her Majesty's Youth Offender Institution
LCI	Lower confidence interval
NHSBT	NHS Blood and Transplant
NICE	National Institute for Health and Care Excellence
NSP	Needle and syringe programme
ONS	Office for National Statistics
PHE	Public Health England
PWID	People Who Inject Drugs
RNA	Ribonucleic acid
UCI	Upper confidence interval
YOI	Youth offender institution

Contents

List of figures 5
List of tables 7
Executive summary 8
Key findings: 8
Recommendations: 11
Introduction 13
Burden of hepatitis C in the North East 16
Laboratory reports of hepatitis C in the North East. 16
Demographics of newly diagnosed hepatitis C cases in the North East 21
Sentinel surveillance data 22
Impact of hepatitis C in the North East 24
Hospital admissions for hepatitis C and related diseases 24
Liver Transplants 24
Deaths from hepatitis C 27
Awareness and Reducing Undiagnosed Infections 29
Trends in testing as an indicator of increased awareness 29
Site of testing 30
Testing and diagnoses in Black, Asian and minority ethnic populations 32
Testing and diagnosis among people in secure and detained settings 34
Testing and diagnosis in people who inject drugs 35
Monitoring the coverage of key services 44
Risk factors associated with HCV infection in the North East 44
Local Initiatives 46
Conclusions 47
Recommendations 48
Data sources 49
References 51
Acknowledgements 52

List of figures

Figure 1 – New diagnoses of Hepatitis C by month and year reported, also showing a 6 month weighted average, 2013 to 2017 16
Figure 2 – Laboratory reports of hepatitis C per 100,000 population, residents of North East PHE Centre and England, 2008 to 2017[,,,] 17
Figure 3 – Laboratory reports of hepatitis C, directly standardised rate (DSR) per 100,000 population by upper tier local authority of residence, North East PHE centre, 2016 and 2017[,,,] 19
Figure 4 – Percentage of reports of hepatitis C by reporting laboratory, North East PHE centre, 2017[,,] 21
Figure 5 – Age and sex of new diagnoses of hepatitis C 2013 to 2017, residents of North East PHE Centre. Cases diagnosed in 2017 are indicated by darker shading.[,,] 22
Figure 6 – Percentage of individuals testing positive for anti-HCV in sentinel laboratories by PHE centre of laboratory, 2013 to 2017 23
Figure 7 – Hospital admissions for individuals* with a diagnosis code for HCV, residents of North East PHE centre, 2013 to 2016[*] 25
Figure 8 – Hospital admissions for individuals[*] with a diagnosis code for HCV-related end-stage liver disease (ESLD), North East PHE centre, 2013 to 2016 25
Figure 9 – Hospital admissions for individuals[*] with a diagnosis code for HCV-related hepatocellular carcinoma (HCC), residents of North East PHE centre, 2013 to 2016 26
Figure 10 – Number of first liver transplants with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant at registration. Or patients who were HCV positive at registration or transplant and the percentage of all liver transplants, North East PHE centre, 2010 to 2013 and 2014 to 2017 26
Figure 11 – Rate of deaths from ESLD or HCC in those with HCV mentioned on their death certificate by PHE Centre, 2008 to 2017 per 100,000 populations 27
Figure 12 – Number of individuals tested and the percentage that tested positive for anti-HCV in sentinel laboratory, North East PHE centre, 2013 to 2017 29
Figure 13 – Number of individuals tested and the percentage that tested positive for anti-HCV in the sentinel laboratory, North East and Cumbria ODN, 2013 to 2017[,] 30
Figure 14 – Number of individuals tested for anti-HCV and the percentage positive by service type in the sentinel laboratory, North East PHE centre, 2013 to 2017^ 31
Figure 15 – Number of individuals tested and the percentage that tested positive for anti-HCV by ethnic group in the sentinel laboratory, North East PHE centre, 2013 to 2017 32
Figure 16 – Number of South Asian individuals tested and testing positive for anti-HCV by ethnicity in the sentinel laboratory, North East PHE centre, 2013 to 2017 33

Figure 17 – Number of Eastern European individuals tested and testing positive for anti-HCV in the sentinel laboratory, North East PHE centre, 2013 to 2017 34
Figure 18 – Number of samples and the percentage of anti-HCV prevalence, PWID, North East region, 2008 to 2017 36
Figure 19 – Percentage anti-HCV prevalence in PWID by Operational Delivery Networks, England, 2016/17 36
Figure 20 – Hepatitis C test uptake among PWID and their awareness of infection, North East region, 2008 to 2017 37
Figure 21 - Number of persons who inject drugs tested and testing positive for anti-HCV at specialist drug services in the sentinel laboratory, North East PHE centre, 2013 to 2017 38
Figure 22 - Percentage of eligible persons in substance misuse treatment who inject drugs who have received a hepatitis C test, North East local authorities 2017 and 2018 39
Figure 23 - Level of direct and indirect sharing of injecting equipment among PWID, North East region, 2008 to 2017 40
Figure 24 – Number of young adults tested and percentage testing positive for anti-HCV in the sentinel laboratory, North East PHE centre, 2013 to 2017 42

List of tables

Table 1 – New laboratory diagnoses of hepatitis C by quarter and year reported in North East residents, 2013 to 2017 17
Table 2 – Laboratory reports of hepatitis C per 100,000 population by PHE centre of residence, 2012 to 2017 18
Table 3 – Number of laboratory reports of hepatitis C, residents of North East PHE centre by upper tier local authority, 2013 to 2017 18
Table 4 – Number and percentage of hepatitis C reports in young adults aged 15 to 24, residents of North East PHE centre, 2013 to 2017 41
Table 5 – Risk exposures for individuals tested for anti-HCV in sentinel laboratory, NE PHE centre, 2013 to 2017 44

Executive summary

Hepatitis C (HCV) remains an important public health problem with the most recent modelled national estimates suggesting that around 143,000 individuals are chronically infected in the UK[1]. Transmission of the virus is through contact with blood or blood product fluids from an infected person, with prevalence most common in marginalised groups, particularly minority ethnic communities with close links to countries with a high prevalence of HCV infection and people who inject drugs (PWID)[2]. Hepatitis C is a 'silent disease' with individuals often presenting with late-stage complications such as end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC), which have poor survival rates. Measures aimed at preventing, managing, and controlling hepatitis C such as Needle and Syringe Exchange Programmes (NSP) and access to effective antiviral drugs continue to reduce the risk of individual infection and limit further spread of the virus.

While progress to eliminate hepatitis C infection continues to be made both nationally and within the North East, further action is needed. Nationally, 2 main impact areas have been identified – the need to reduce the number of people becoming seriously ill or dying from the infection, and reducing the number of people who become newly infected or re-infected. Progress has been made in both areas, following the distribution of direct acting drugs (DAAs), which were introduced over 2014 to 2015, the rollout of opt-out blood-borne virus (BBV) testing in prisons and the expansion of testing and treatment in drug services through the work of the Hepatitis C Operational Delivery Networks.

This report is part of a series of annual updates to summarise the progress made in the North East to reduce the risk of infection, prevent further transmission of HCV, and improve the health outcomes of people with hepatitis C. It contains indicators intended for the monitoring of the coverage of interventions to drive the reduction of HCV infection and HCV-related mortality in the UK and meet World Health Organization (WHO) global hepatitis C targets introduced in 2016.

Key findings

Burden

In 2017, hepatitis C laboratory reports increased by 51% in the North East. This may have arisen from an expanded opt-out BBV testing in prisons in the region, in combination with the work to expand testing and treatment in non-clinical settings undertaken by the North East and Cumbria Operational Delivery Network (NEC ODN).

The North East has had consistently lower hepatitis C rates reported compared to the average rate for England.
Laboratory reports varied by local authority with the highest rates of HCV diagnoses in Middlesbrough and Gateshead, both having a DSR per 100,000 significantly higher than the England figure in 2017. Six local authorities reported a DSR significantly lower than the England rate. Compared to 2016, reporting rates were generally higher with 3 local authorities having DSRs significantly higher than last year. As mentioned earlier, local initiatives to identify and screen individuals at risk expanded in 2017 – however, given the limitations in laboratory data it is not possible to determine whether the higher reporting was due to higher disease incidence or higher testing and reporting.

Cases of HCV were most commonly reported in those aged 35 to 44 years, both in 2017 and in the period of 2013 to 2017. Cases were predominantly in males with only 28% of laboratory reports being from females in 2017.

The percentage of individuals testing positive for HCV over 2013 to 2017 in the North East sentinel laboratory was the lowest figure in England – significantly lower than the England average. However, the 2017 annual figure (1.8%) was among the highest nationally, suggesting that local testing initiatives were reaching those more likely to have infection.

Impact

Hospital admissions data for 2017 was unavailable due to data misclassification preventing the deduplication of records submitted in late 2017 (see below). However, in 2016 the negative impact of HCV in the North East was low, with hospital admissions for HCV and HCV related ESLD being stable, and hospital admissions for HCV related HCC decreasing.

Nationally between 2008 to 2017, the North East was among the lowest for regional rates of deaths from ESLD or HCC in individuals with a diagnosis code for HCV. The number of people with HCV registering for a transplant in the region halved between 2010 to 2013 and 2014 to 2017.

Service coverage

The number of people tested for HCV in the North East sentinel laboratory has increased between 2013 to 2017. The proportion of those tested positive remained relatively stable around 1.0% until 2015, and has risen to 1.8% in 2017 although this should be interpreted with caution, as the proportion positive might have, to some extent, be influenced by the amount of confirmatory tests performed at the North East sentinel laboratory.

During 2013 to 2017, testing was predominantly carried out at GUM clinics and ‘other ward types’ (which includes, but does not specify: cardiology, dermatology haematology, ultrasound, and x-ray wards) – however, the proportion of those who tested positive at these sites was low. The highest proportion of positive tests were from drug dependency and unspecified wards, although the number tested at such sites were low. This was likely due to an underestimation of testing as sentinel data excludes DBS and oral fluid tests, which are commonly used in such settings.

According to sentinel surveillance, testing was highest in those of White ethnicity which reflects the demographics of the North East, with low numbers of tests performed in those of Black, Asian and Minority Ethnic ethnicities. By broad ethnic group, the highest proportion of positive tests was also seen in those of White ethnicity (2.2%). People of Eastern European origin reported 5.4% positivity, although the number of tests performed in this population are very low. Positivity has fluctuated over the period of 2013 to 2017 in those of South Asian origin, although it reached its lowest level of 0.9% in 2017, compared with 1.6% in 2013.

There has been an increasing trend in anti-HCV prevalence in people who inject drugs (PWID) who responded to the Unlinked Anonymous Monitoring (UAM) survey in the North East since 2008, with 37% of UAM samples positive for anti-HCV in 2017. This increase was to some extent attributed to the introduction of DBS testing, which is more sensitive than the previously used oral fluid tests.

The proportion of PWID sharing injecting equipment has decreased over the past decade nationally, however, North East data suggests that the regional trend over this period has remained stable. Self-reported testing uptake increased both in the North East and nationally in 2017, with uptake in the North East comparable to the figures for England, Wales and Northern Ireland overall. The proportion of survey participants aware of their hepatitis C status in the North East has also increased, although the figure was significantly lower than that seen nationally.

HCV test uptake of eligible people in substance misuse treatment reported in 5 North East local authorities (Stockton-on-Tees, Gateshead, Redcar and Cleveland, Hartlepool and South Tyneside) was significantly higher than the England and North East region average, while uptake in a further 3 local authorities in the region was significantly lower than the national and regional averages.

The proportion of young adults (aged 15 to 24 years) testing positive for HCV, a proxy measure of incidence in drug users, has shown a general decrease in trend since 2012. However, these figures should be treated with caution as demographic changes in the population being tested may have diminished the impact of this age group in the proportion of positive samples.

In the North East sentinel laboratory dataset between 2013 and 2017, the risk exposure information or the reason for testing was known in 74.8% of cases. Where specified, the biggest risk exposure/reason for testing was screening (24%) and injecting drug use (17%). Data from sentinel surveillance suggests that the number of drug users referred by specialist drug services for HCV testing has decreased in 2017, while the proportion testing positive has increased. These data should be interpreted with caution, as sentinel surveillance may not be representative as it does not fully capture DBS testing in the region.

Nationally in 2017/2018, 26% of all new prison receptions were tested for hepatitis C within 31 days.

Recommendations

Reducing the number of people becoming infected

The number of people testing positive in the North East overall has remained relatively stable since 2012. Raising public awareness remains an important component of reducing the burden of HCV infection. Engagement of the third sector, for example charities such as the Hepatitis C Trust, is useful in accessing groups at high risk of infection through peer support and should continue to be a key aspect of outreach.

The level of needle and syringe sharing among those currently injecting psychoactive drugs has fallen across the UK but there has been a gradual increase in the proportion of PWID who reported sharing of injecting equipment in the North East. It is vital that a broad range of harm reduction and specialist treatment services are made available in diverse settings. Interventions encouraging reduction or cessation of injection as a route of consumption, in combination with adequate injecting-related equipment provision should be sustained to reduce needle sharing.

Increasing the number of people diagnosed

As well as increasing public awareness, it is important to maintain and improve awareness among health professionals. All stakeholders should continue to improve awareness among health professionals in contact with HCV patients and should receive regular updates on regional testing and treatment strategies.

There has been a slight decrease in voluntary hepatitis C testing in PWID in the North East. Stigma and discrimination are thought to be key drivers that influence declining the offer of a test, highlighting the importance of expanding awareness among this group.

Increasing the number of those diagnosed who access treatment

Those responsible for commissioning HCV treatment services should continue to work with all stakeholders to ensure equitable access to treatment, and to increase access to direct-acting antiviral agents (DAA).

One of the biggest identified obstacles to treatment access for HCV is the lack of treatment settings suitable for PWID. Multidisciplinary and peer-supported programmes should continue to be expanded, and blood-borne virus (BBV) testing should be encouraged in diverse settings to enable rapid referral to a treatment pathway.

Introduction

Hepatitis C (HCV) remains an important public health concern with the most recent modelled national estimates suggesting that around 143,000 individuals are chronically infected in England[1]. Transmission of the virus is through contact with blood or blood products fluids from an infected person, with injecting drug use being an important risk factor for infection[2].

Hepatitis C is a 'silent disease' with the majority of infections asymptomatic, making it difficult to estimate true incidence and prevalence. As a result, presentation with the infection is often at later stages with complications such as hepatitis C-related end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC), which have poor survival rates. Although registered deaths from HCV-related ESLD and HCC more than doubled between 2005 and 2014[1], since 2014 deaths have been falling, with a decline of 16.3% between 2014 and 2017. While these figures should be interpreted with caution, this fall in the number of deaths may be an indication of the increased use of direct-acting antiviral (DAA) drugs having an impact in those with advanced disease[1].

Worldwide, the burden of hepatitis has been increasing since 1990, with viral hepatitis a leading cause of death globally. In May 2016, WHO adopted a Global Health Sector Strategy (GHSS) with the first global targets for the viral hepatitis, including a 30% reduction in new cases of HCV and a 10% reduction is HCV-related mortality by 2020, and 90% of people with chronic HCV diagnosed by 2030[3]. Reports suggest that the UK is well placed to meet the GHSS mortality targets, in part due to the increased availability of DAA drugs[1]. There has been a steady increase in testing over the past decade, which has allowed the Hepatitis C Operational Delivery Networks (ODNs) to embark on work to maximise linkage to care. Although this increase is promising, more needs to be done to increase engagement of risk groups and equity of treatment and care services if the UK is to meet the target of 90% of HCV-positive people diagnosed by 2030.

The focus of Public Health England's approach to support the WHO in eliminating hepatitis C as a major public health threat by 2030 is captured in the PHE vision statement as per below[4].

> 'All people at risk of HCV virus infection should have access to testing and, once tested, action should be taken to either reduce their risk of infection or prevent further transmission of the virus, and – if viraemic – place the patient on a treatment pathway'

This report is part of a series of annual updates that summarise the progress made by the North East in reducing the risk of infection, preventing further transmission of HCV,

and improving the health outcomes of people with hepatitis C. It is produced to support local and regional action towards hepatitis C prevention, testing, treatment and care. Furthermore, as this report summarises the 2017 picture of HCV in the North East, it can be used to identify gaps where action is needed to meet the GHSS goals for 2020 and 2030, and to help inform local ODN activity.

Data sources

Laboratories in the UK routinely report blood samples positive for the antibody to hepatitis C (anti-HCV) and this has been a statutory requirement since October 2010[5]. A positive test to anti-HCV indicates that a person has been exposed to hepatitis C – it cannot distinguish between a current and past infection. For this reason, these laboratory reports are only reflective of patterns of testing rather than trends in incidence or prevalence. Acute hepatitis C cases are rarely symptomatic – therefore, the majority of reported infections are chronic.

From 2016, individuals aged less than one year, in whom positive tests may reflect the presence of passively acquired maternal antibody rather than true infection, are excluded.

This report is based on data from a variety of surveillance sources up to and including 2017 (unless otherwise specified). Data on hepatitis C morbidity and mortality (and related data) was obtained from sentinel laboratory surveillance, anonymised prevalence monitoring surveys of PWID, Hospital Episode Statistics (HES), NHS Blood and Transplant (NHSBT), and the Office for National Statistics (ONS). Routine laboratory surveillance data was obtained from the North East surveillance system, EpiNorth3.

Please note: national laboratory surveillance figures have been consistently lower than EpiNorth3 figures for hepatitis C cases in the North East. This is thought to arise from allocation and de-duplication issues, in addition to the inclusion of DBS testing in the EpiNorth3 dataset. National data is assigned to the region of laboratory if both patient and GP postcode are unknown and in earlier years these postcodes were not routinely provided. Furthermore, national data is de-duplicated based on data from all regions – the North East centre does not have access to this data and so may overestimate the number of cases.

The sentinel surveillance of blood-borne virus testing was set up in 2002 to enhance routine laboratory surveillance of hepatitis C – it collects data on laboratory test results and demographic and risk factor data for all individuals tested for the hepatitis C antibody in 18 sentinel laboratories in England, covering approximately 40% the population[6]. Limitations of the data include some duplication of individual patients and exclusion of dried blood spot, oral fluid, reference testing, and testing from hospitals

referring all samples which do not have the original location identified. Historical sentinel surveillance data for 2017 is not comparable to figures released for previous years. This is due to a number of reasons, such as differing completeness of services reporting to the sentinel laboratory between years, changes in reporting methodology and increasing numbers of reports from private laboratories.

As infection is often highest in marginalised groups such as PWID, anonymous testing and surveys are used to gather data on prevalence and risk factors for infection. The Unlinked Anonymous Monitoring (UAM) survey of PWID is an annual cross-sectional survey of individuals who currently or previously inject psychoactive drugs who are in contact with specialist services. Those who agree to take part provide a biological specimen that is tested anonymously for HIV, hepatitis C and hepatitis B. Behavioural and limited demographic information is collected through a brief anonymous subject-completed questionnaire linked to the specimen but unlinked from any client identifying information. The biological sample collected in the survey was changed from an oral fluid to a dried blood spot (DBS) during 2009 and 2010. From 2011 onwards, only DBS samples have been collected. The sensitivities of the tests on a DBS sample for antibodies to hepatitis C and hepatitis B core antigen are close to 100%. The sensitivity of the oral fluid sample test for antibodies to hepatitis C is about 92% and that for antibodies to the hepatitis B core antigen is about 75%. Regional level data should be interpreted cautiously as the survey recruits participants through a nationally reflective sample of the services provided to PWID.

HES data for 2017 on admissions are not available for England due to incorrect classification by NHS Digital of some HCV codes as ‘restricted’. This resulted in identifiers which link admissions to a specific patient being stripped from HCV coded data sent by providers to NHS Digital. The error is a temporary issue which affected some data submitted between December 2017 and May 2018 and is now fixed. However, it means that it was not possible to de-duplicate individuals and identify multiple patient admissions in 2017.

Burden of hepatitis C in the North East

Laboratory reports of hepatitis C in the North East

It is difficult to accurately determine the burden of hepatitis C as infections are usually asymptomatic in the initial stages with many people unaware they have the virus. As laboratory tests are unable to distinguish between new and chronic infections, laboratory reporting generally reflects trends in testing and reporting rather than trends in incidence, with the greater majority of detected infections representing new diagnoses of chronic infections. Changes in rates of diagnosis must therefore be interpreted with caution. Furthermore, cases are reported following an initial screening test through detection of HCV antibody (alone or in combination with HCV antigen) which can signify current infection or past infection (treated or spontaneously cleared). Confirmatory tests detecting HCV antigen and/or HCV RNA are reported less consistently, it is therefore not possible to differentiate between cases with active and past infections.

In 2017, 367 cases of hepatitis C were reported by laboratories to PHE in the North East and (Figure 1 and Table 1). This was higher than the number of cases reported in 2016 (243). This increase in reporting in the North East contrasted with the slight downward trend in laboratory reporting observed nationally (Figure 2).

Figure 1 – New diagnoses of Hepatitis C by month and year reported, also showing a 6 month weighted average, 2013 to 2017

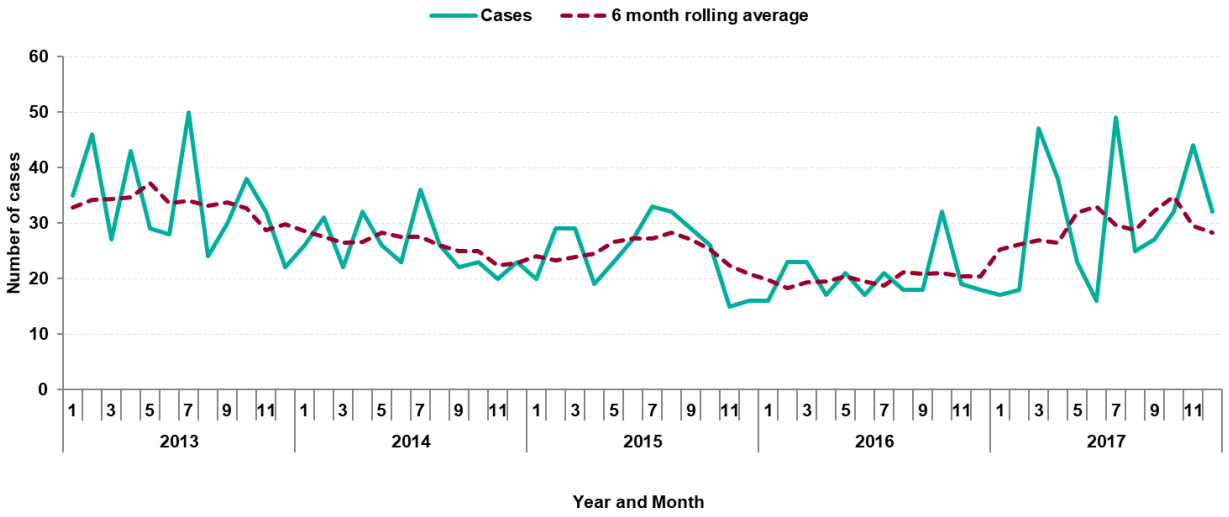
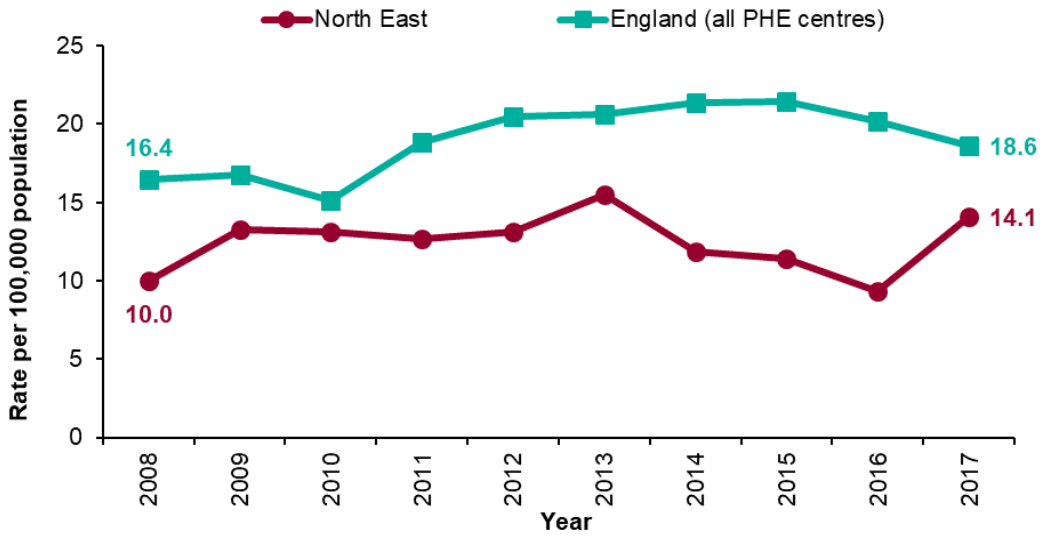


Table 1 – New laboratory diagnoses of hepatitis C by quarter and year reported from the North East, 2013 to 2017

Quarter	2013	2014	2015	2016	2017	Total
1	108	79	79	62	82	410
2	100	81	69	55	76	381
3	104	84	94	57	101	440
4	92	66	57	69	108	392
Total	404	310	299	243	367	1623

As in previous years, in 2017 the crude rate of laboratory-reported HCV infections in the North East remained below the England rate (14.1 per 100,000 population vs. 18.6 per 100,000; Figure 2) – however, the North East rate increased substantially from the previous year (9.3 per 100,000 in 2016). Rates of hepatitis C reports by PHE centre are detailed in Table 2, and show that the North East continued to have one of the lowest rates of laboratory reporting by PHE Centre in England despite the increase in 2017.

Figure 2 – Laboratory reports of hepatitis C per 100,000 population, residents of North East PHE Centre and England, 2008 to 2017*,†,‡,§



Rates per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS).

* National figures have been consistently lower than local figures for the number of hepatitis C cases in the North East. This is thought to arise from allocation and de-duplication issues. EpiNorth3 data from the North East may overestimate the number of new cases as the surveillance system is not able to de-duplicate cases previously reported outside of the region

† Data are summarised by PHE centre of residence, not PHE centre of laboratory. Data are assigned to PHE centre by patient postcode where present – if patient postcode is unknown, data are assigned to PHE centre of registered GP practice; where both patient postcode and registered GP practice are unknown data are assigned to PHE centre of laboratory.

‡ Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.

§ Mothers who are anti-HCV positive usually pass this maternal antibody to their newborns. However most of these newborns are not actually infected with the hepatitis C virus. The antibodies showing up in the newborn's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life. Therefore, the baby will have a positive anti-HCV test irrespective of whether the baby is infected. For this reason, tests in those aged under one are excluded from the dataset for 2016 and 2017.

Table 2 – Laboratory reports of hepatitis C per 100,000 population by PHE centre of residence, 2012 to 2017

PHE centre of residence	2012	2013	2014	2015	2016	2017
East Midlands	15.3	12.2	13.3	11.5	14.9	15.6
East of England	11.9	11.2	12.6	14.1	16.7	16.1
London	33.3	36.9	45.9	47.0	45.2	36.1
North East	13.1	15.5	11.8	11.4	9.3	14.1
North West	25.9	28.0	21.1	19.2	12.8	13.0
South East	15.9	13.1	15.6	14.9	13.9	12.0
South West	21.0	18.7	17.7	19.5	15.4	16.8
West Midlands	13.2	13.7	11.4	15.2	20.1	17.9
Yorkshire and Humber	25.9	27.5	28.5	24.7	18.4	18.9
Total	20.5	20.7	21.4	21.4	20.2	18.6

Laboratory reports of hepatitis C by North East local authority

In the North East, the number and rate of laboratory reports of hepatitis C infection varied across upper-tier local authorities (Table 3). In 2017, the highest rate of HCV diagnoses were in Gateshead and Middlesbrough (31.0 and 28.1 per 100,000 respectively) and the lowest was in Redcar and Cleveland (3.7 per 100,000).

Table 3 – Number of laboratory reports of hepatitis C, residents of North East PHE centre by upper tier local authority, 2013 to 2017[*,†]

Upper tier local authority of residence	Number of laboratory reports					Laboratory reports per 100,000 population					
	2013	2014	2015	2016	2017	2013	2014	2015	2016	2017	Trend
County Durham	100	79	58	53	55	19.4	15.3	11.2	10.3	10.6	
Darlington	23	20	15	24	19	21.8	18.9	14.2	22.8	18.1	
Gateshead	44	44	40	33	62	22.0	21.9	19.8	16.5	31.0	
Hartlepool	14	11	7	14	17	15.1	11.9	7.6	15.3	18.5	
Middlesbrough	53	18	39	25	39	38.2	13.0	28.0	18.1	28.1	
Newcastle upon Tyne	36	19	20	23	52	12.6	6.6	6.9	7.9	17.8	
North Tyneside	19	4	6	6	18	9.4	2.0	3.0	3.0	8.9	
Northumberland	32	43	30	18	25	10.1	13.6	9.5	5.7	7.9	
Redcar and Cleveland	11	12	11	6	5	8.2	8.9	8.1	4.5	3.7	
South Tyneside	15	12	19	7	34	10.1	8.1	12.8	4.7	23.0	
Stockton-on-Tees	29	21	11	11	11	15.0	10.8	5.6	5.7	5.7	
Sunderland	28	27	33	19	28	10.1	9.8	11.9	6.9	10.2	
Total	404	310	289	239	365	15.5	11.8	11.0	9.2	13.9	

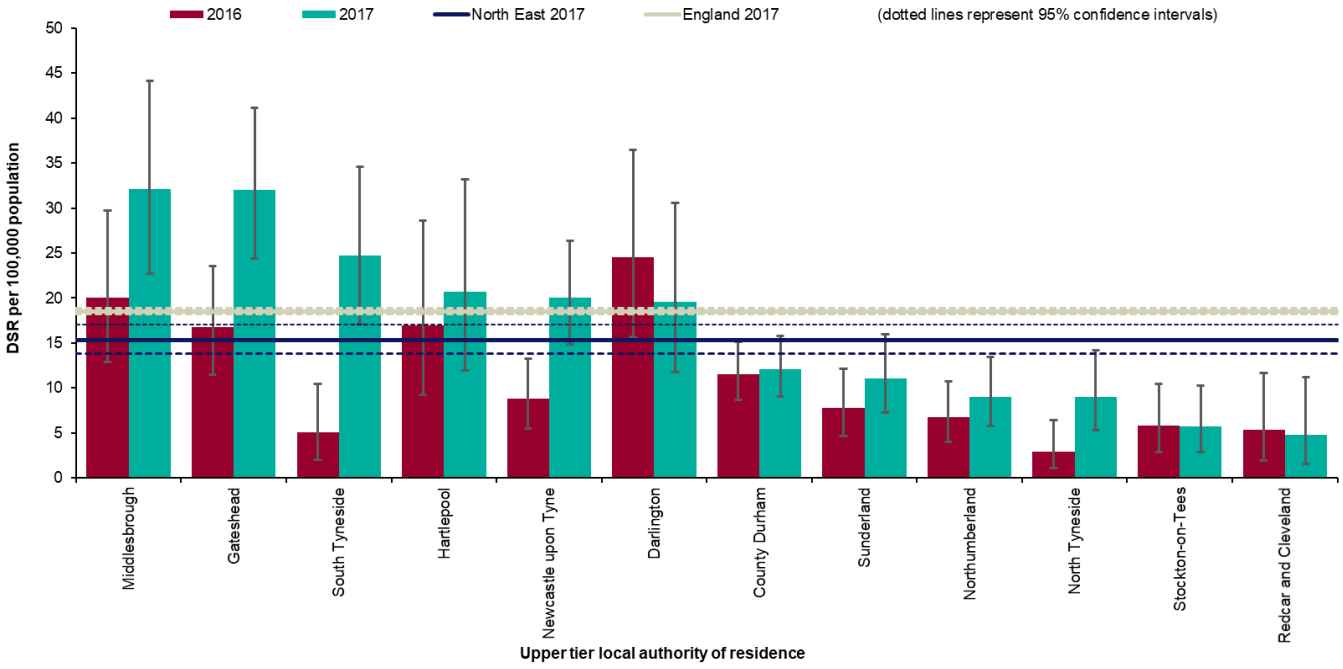
Rates per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS).

[*] Data are summarised by upper tier local authority of residence, not upper tier local authority of laboratory. Data are assigned to upper tier local authority by patient postcode where present – if patient postcode is unknown, data are assigned to upper tier local authority of registered GP practice, where both patient postcode and registered GP practice are unknown data are assigned to upper tier local authority of laboratory.

[†] Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.

Variation between local authority areas was also observed when directly standardised rates (DSR) were applied (used to compare populations which differ in one or more underlying characteristic, for example age or sex). The DSR per 100,000 population showed that 6 local authorities (County Durham, Sunderland, Northumberland, North Tyneside, Stockton-on-Tees, and Redcar and Cleveland) in the North East had a DSR of laboratory reporting significantly lower while 2 areas reported significantly higher DSRs (Middlesbrough and Gateshead) than the England figure for 2017. However, no local authorities reported significantly lower DSRs in 2017 than 2016 (Figure 3).

Figure 3 – Laboratory reports of hepatitis C, directly standardised rate (DSR) per 100,000 population by upper tier local authority of residence, North East PHE centre, 2016 and 2017*,†,‡,§



Key findings

In 2017, HCV laboratory reports increased by 51% in the North East. This may have arisen from an expanded rollout of opt-out BBV testing in North East prisons in combination with the work to expand testing and treatment in non-clinical settings undertaken by the North East and Cumbria Operational Delivery Network. The North East has had consistently lower reporting rates compared to the average rate of reporting in England.

* Data are summarised by upper tier local authority of residence, not upper tier local authority of laboratory. Data are assigned to upper tier local authority by patient postcode where present – if patient postcode is unknown, data are assigned to upper tier local authority of registered GP practice, where both patient postcode and registered GP practice are unknown data are assigned to upper tier local authority of laboratory.

† Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.

‡ DSRs per 100,000 population have been calculated using mid-year population estimates supplied by the Office for National Statistics (ONS).

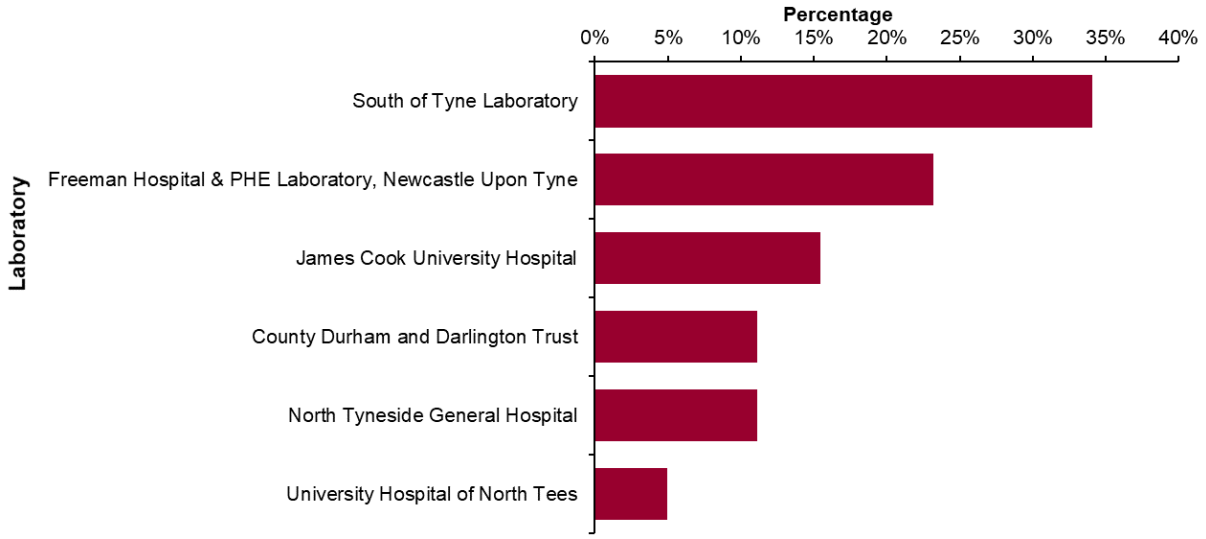
§ Excludes cases where age and/or gender are unknown.

Laboratory reports varied by local authority with the highest rates of HCV diagnoses in Middlesbrough and Gateshead, both having a DSR per 100,000 significantly higher than the England figure in 2017. Six local authorities reported a DSR significantly lower than the England rate. Compared to 2016, reporting rates were generally higher with 3 local authorities having DSRs significantly higher than last year. As mentioned earlier, local initiatives to identify and screen individuals at risk expanded in 2017 – however, given the limitations in laboratory data it is not possible to determine whether the higher reporting was due to higher disease incidence or higher testing and reporting

Reports by laboratory

In 2017, 323 reports of hepatitis C in North East residents were reported from laboratories in the North East (Figure 4). The highest proportion of reports were from the South of Tyne Laboratory (34%; n=110) with the lowest proportion from University Hospital of North Tees (4%; n=14). Additional 44 cases were reported in North East residents from laboratories outside of the region, which included 32 DBS and 8 blood/serum tests performed at the Manchester Royal Infirmary and 4 blood sample tests reported from laboratories in Leeds, Truro, Birmingham and London. As previously stated, increases in laboratory reporting do not necessarily indicate an increase in incidence. Rather, the trend in laboratory reporting may suggest changes in testing and reporting, and may be influenced by local initiatives to identify and screen those at risk.

Figure 4 – Percentage of reports of hepatitis C by reporting laboratory, North East PHE centre, 2017*,†,‡



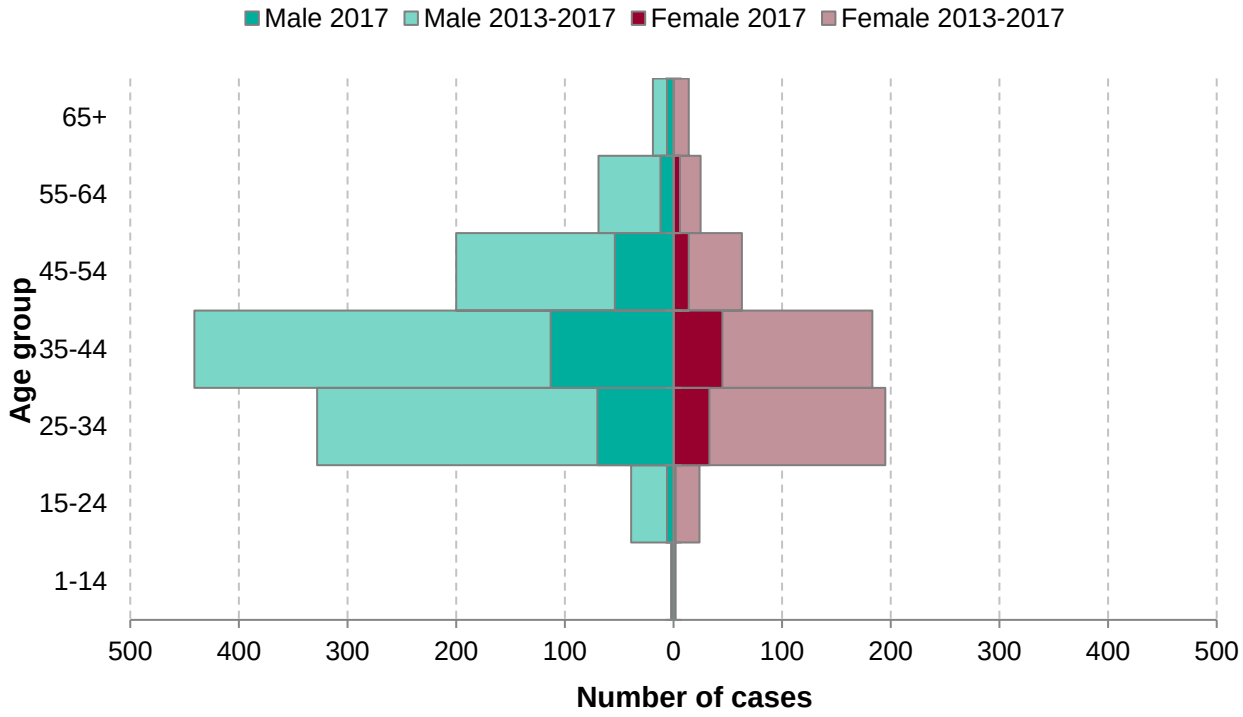
NB: South of Tyne Laboratory incorporates referrals from Queen Elizabeth Hospital (Gateshead), Sunderland Royal Hospital and South Tyneside Hospital.
County Durham and Darlington Trust incorporates referrals from Darlington Memorial Hospital and University Hospital of North Durham.

Demographics of newly diagnosed hepatitis C cases in the North East

Overall, in the period between 2013 and 2017, 1095 male (68.4%) and 506 female (31.6%) North East residents were reported to be HCV positive (Figure 5). In 2017, over two-thirds of laboratory reports were in men (71.5% vs. 28.5% female), which was slightly higher than the proportion in England overall (67%). Reports of HCV were most common in persons aged between 25 to 54 years (86% of cases) – with the highest proportion of male and female cases occurring in the 35 to 44 year age group (Figure 5). Figures reported in 2017 for males reflected the trend in age and sex distribution observed in the period between 2013 and 2017. The 2017 figures for females differed slightly with greater number of cases reported in the 15 to 24 age group in 2017 compared to 2013 to 2017.

* Data are summarised by PHE centre of laboratory
† Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.
‡ Mothers who are anti-HCV positive usually pass this maternal antibody to their newborns. However most of these newborns are not actually infected with the hepatitis C virus. The antibodies showing up in the newborn's blood are most often the mother's antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life. Therefore, the baby will have a positive anti-HCV test. irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the dataset for 2016 and 2017.

Figure 5 – Age and sex of new diagnoses of hepatitis C 2013 to 2017, residents of North East PHE Centre. Cases diagnosed in 2017 are indicated by darker shading.*,†,‡



In England, HCV infection tends to be concentrated in areas with a high proportion of current/former injecting drug users and in areas with high numbers of people from ethnic groups with links to high prevalence countries[4]. However, ethnicity is not routinely recorded in laboratory reports and was not recorded in any laboratory episodes referred in the North East in 2017.

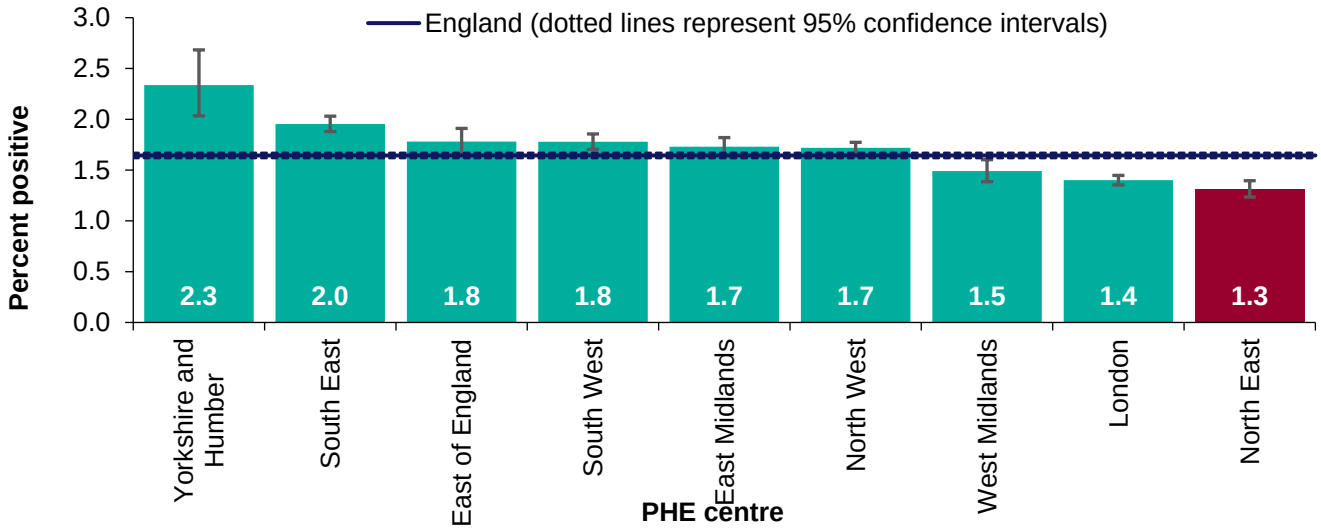
Sentinel surveillance data

Sentinel surveillance of hepatitis aims to supplement routine laboratory surveillance of hepatitis viruses in England by monitoring trends in testing, which are useful for monitoring the impact of awareness-raising and prevention activities[6]. The North East has one sentinel laboratory (Freeman Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust), which participates in the PHE sentinel surveillance of hepatitis testing. As a result, caution should be exercised when interpreting sentinel surveillance data as the data may not be representative of overall regional trends.

* Data are summarised by PHE centre of residence, not PHE centre of laboratory. Data are assigned to PHE centre by patient postcode where present – if patient postcode is unknown, data are assigned to PHE centre of registered GP practice; where both patient postcode and registered GP practice are unknown data are assigned to PHE centre of laboratory.
† Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.
‡ Chart excludes cases where gender and/or age are unknown.

Between 2013 and 2017, a total of 77,096 individuals were tested by the North East sentinel laboratory to detect antibodies against HCV (anti-HCV; Figure 6). Of these tests, 1,012 were positive (1.3%, 95% CI: 1.2-1.4%), which was the lowest proportion in England between 2013 and 2017 (England average 1.6%). However, in 2017, 17,601 individuals were tested for anti-HCV in the North East sentinel laboratory, with 315 (1.8%) testing positive. The 2017 figure was higher than the national average for 2017 (1.6%) and was among the highest positivity rates reported nationally.

Figure 6 – Percentage of individuals testing positive for anti-HCV in sentinel laboratories by PHE centre of laboratory, 2013 to 2017*



Key findings

Cases of HCV were most commonly reported in those aged 35 to 44 years, both in 2017 and in the period of 2013 to 2017. Cases were predominantly in males with only 28% of laboratory reports being from females in 2017.

The percentage of individuals testing positive for HCV over 2013 to 2017 in the North East sentinel laboratory was the lowest figure in England, and was significantly lower than the England average. However, the 2017 figure (1.8%) was among the highest nationally, suggesting that local testing initiatives were reaching those most likely to have infection

* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

Impact of hepatitis C in the North East

Progress needs to be made locally and nationally to reduce the numbers of people becoming infected and to reduce the numbers of infected people who become seriously ill or die from hepatitis. Monitoring hospital admissions for HCV-related conditions gives an indication of morbidity and mortality associated with HCV, allowing the impact of infection to be monitored. In England, the overall trend in morbidity and mortality from hepatitis C has been increasing as chronic undetected or untreated infections progress to HCV-related end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC). Deaths from hepatitis C-related ESLD and HCC in the UK almost doubled over the period 2005 to 2015[1]. However, from 2010 to 2015 the number of cases of ESLD/HCC nationally remained stable[4].

Hospital admissions for hepatitis C and related diseases

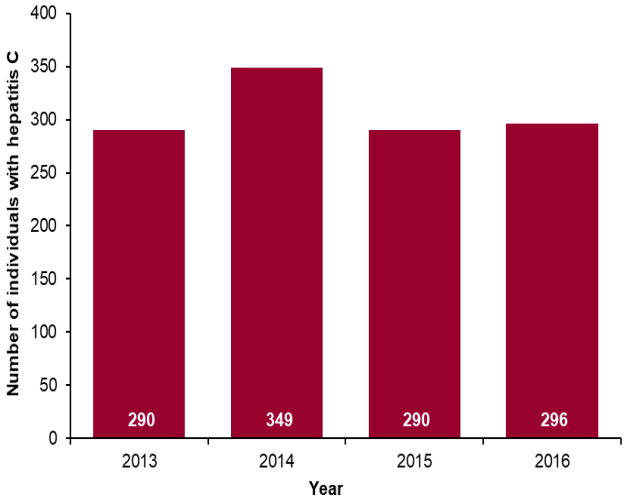
Hospital Episode Statistics (HES) data for 2017 was unavailable due to data misclassification preventing the deduplication of records submitted in late 2017. HES data for 2016 is presented.

In the North East, hospital admissions for HCV remained consistent in 2015 and 2016 (290 and 296 cases respectively), following a decrease from the peak of 349 cases in 2014 (Figure 7). The number of individuals hospitalised with HCV-related end-stage liver disease (ESLD) also remained constant between 2013 and 2016, with 45 individuals admitted to hospital in 2016 (Figure 8). Hospitalisations with HCV-related HCC in North East residents decreased from 6 cases of HCC in 2015 to below 5 (figure suppressed to prevent possible identification of individuals) in 2016 (Figure 9).

Liver transplants

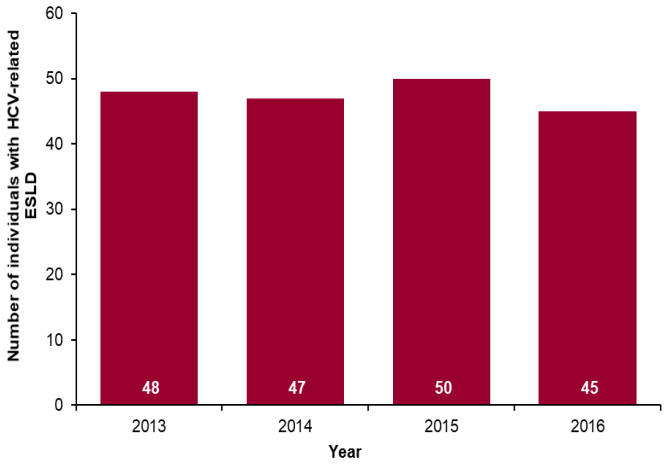
A marker of HCV-related morbidity is the number of individuals with post-hepatitis C cirrhosis as the primary, secondary or tertiary indication for transplant registering at NHS Blood and Transplant for a liver transplant. Between 2014 and 2017 the number of people first registering for a transplant in the North East was substantially lower when compared to between 2010 and 2013 (n=7 vs. n=19). Furthermore, the number of transplants undertaken also decreased between 2014 and 2017 when compared to between 2010 and 2013 (8 vs. 17), with the number of transplants carried out in individuals with post-HCV cirrhosis also decreasing as a percentage of all liver transplants performed (6% vs. 12%; Figure 10). While the numbers in the North East were small, this decrease was also observed at the national level, suggesting that a result of DAA treatments may be limiting the need for patients to be put onto the transplant list.

Figure 7 – Hospital admissions for individuals*[*] with a diagnosis code for HCV, residents of North East PHE centre, 2013 to 2016[*]



Data based on Hospital Episode Statistics as at July 2018

Figure 8 – Hospital admissions for individuals[*] with a diagnosis code for HCV-related end-stage liver disease (ESLD)[†], North East PHE centre, 2013 to 2016[‡]



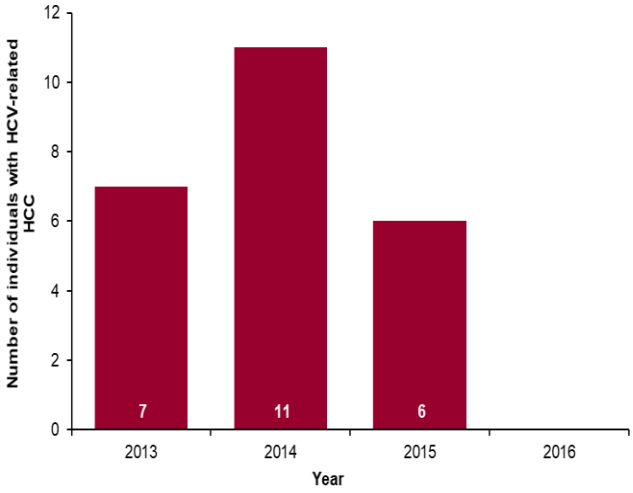
Data based on Hospital Episode Statistics as at July 2018

* Patient counts are based on the unique patient identifier, HESID. This identifier is derived from a patient's date of birth, postcode, sex, local patient identifier and NHS number, using a standard algorithm. Where data are incomplete, HESID might wrongly link episodes or fail to recognise episodes for the same patient. Care is therefore needed, especially where the data includes duplicate records. Patient counts must not be summed across a table where patients may have episodes in more than one cell.

† Defined by codes for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy, hepatic failure.

‡ Patients who have had more than one hospital episode with a diagnosis of HCV, ESLD or HCC in any one year and who have moved residence within that year have been grouped into the PHEC of their latest hospital episode in that year.

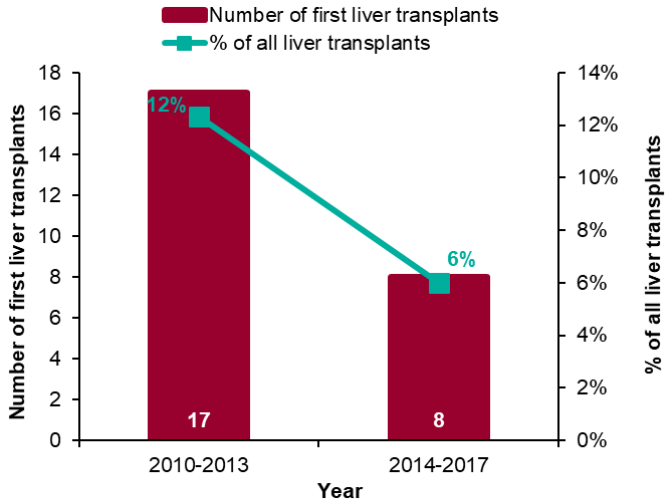
Figure 9 – Hospital admissions for individuals* with a diagnosis code for HCV-related hepatocellular carcinoma (HCC)*, residents of North East PHE centre, 2013 to 2016



Data based on Hospital Episode Statistics as at July 2018

Data source: Hospital Episode Statistics (HES), NHS Digital (NHS Digital is the trading name of the Health and Social Care Information Centre. Copyright © 2019, Re-used with the permission of NHS Digital. All rights reserved). Produced by Public Health England.

Figure 10 – Number of first liver transplants with post-hepatitis C cirrhosis as primary, secondary or tertiary indication for transplant at registration. Or patients who were HCV positive at registration or transplant and the percentage of all liver transplants, North East PHE centre, 2010 to 2013 and 2014 to 2017



Data source: UK Transplant Registry held by NHS Blood and Transplant

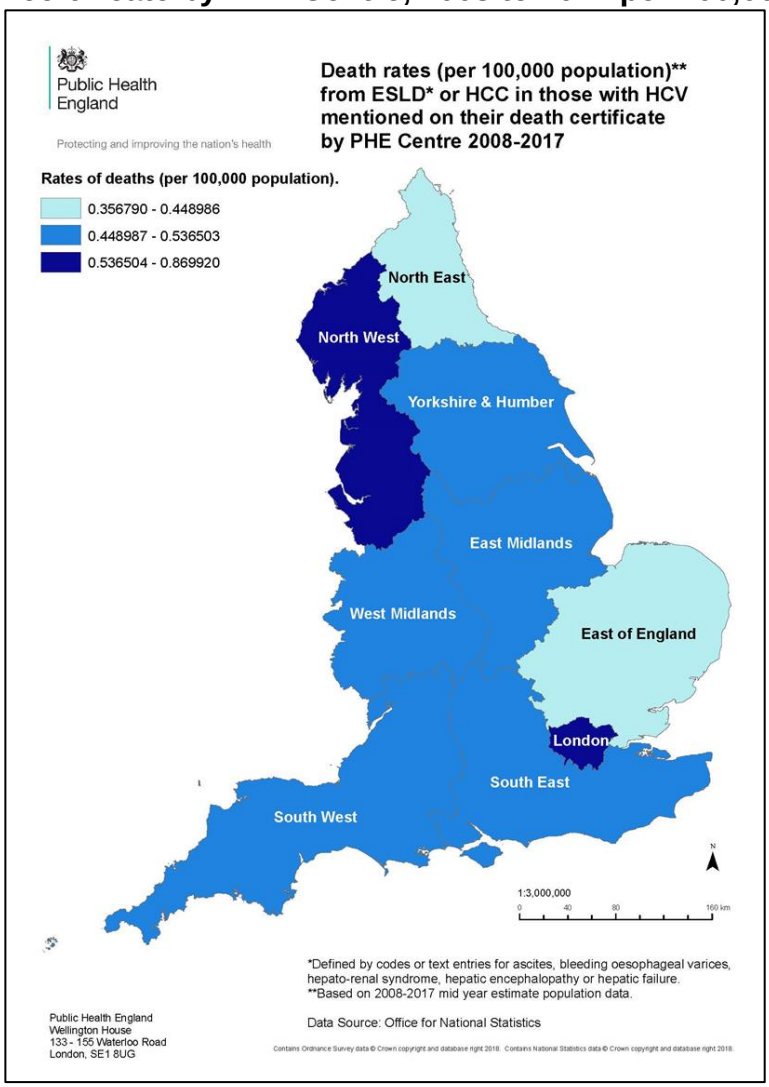
These figures are based on registry data as at 5 August 2018 and include both elective and super urgent registrations.

* For 2016 HCV-related HCC data, cells with values from 1 to 7 have been suppressed to prevent possible identification of individuals. All other counts and totals have been rounded to the nearest 5.

Deaths from hepatitis C

Figure 11 shows the death rate per 100,000 population from ESLD or HCC in individuals with HCV mentioned on their death certificate for the 10-year period from 2008 to 2017. The HCV-related death rate in the North East between 2008 and 2017 was among the lowest nationally and was comparable to the East of England (0.36-0.48 per 100,000).

Figure 11 – Rate of deaths from ESLD or HCC in those with HCV mentioned on their death certificate by PHE Centre, 2008 to 2017 per 100,000 populations†



† Methodology used to create this map is in line with that used in the "2nd Atlas of variation in risk factors and healthcare for liver disease in England" (numerator = aggregate numbers of deaths by PHEC, denominator = mid-year population estimates by PHEC for 2010 - 2017). Changes have been made to the way deaths are counted this year, moving away from monitoring deaths (registered in England) in the year they occurred to monitoring deaths according to the year they were registered where postcodes of individuals' usual place of residence were in England

Changes have been made to the way deaths are counted this year, moving away from monitoring deaths (registered in England) in the year they occurred to monitoring deaths according to the year they were registered where postcodes of individuals' usual place of residence were in England.

Key findings

Hospital admissions data for 2017 was unavailable due to data misclassification preventing the deduplication f records submitted in early 2018. However, in 2016 the negative impact of HCV in the North East was low, with hospital admissions for HCV and HCV related ESLD stable, and hospital admissions for HCV related HCC decreasing.

Nationally between 2008 and 2017, the North East was among the lowest for regional rates of deaths from ESLD or HCC in individuals with a diagnosis code for HCV. The number of people with HCV registering for a transplant in the region halved between 2010 to 2013 and 2014 to 2017.

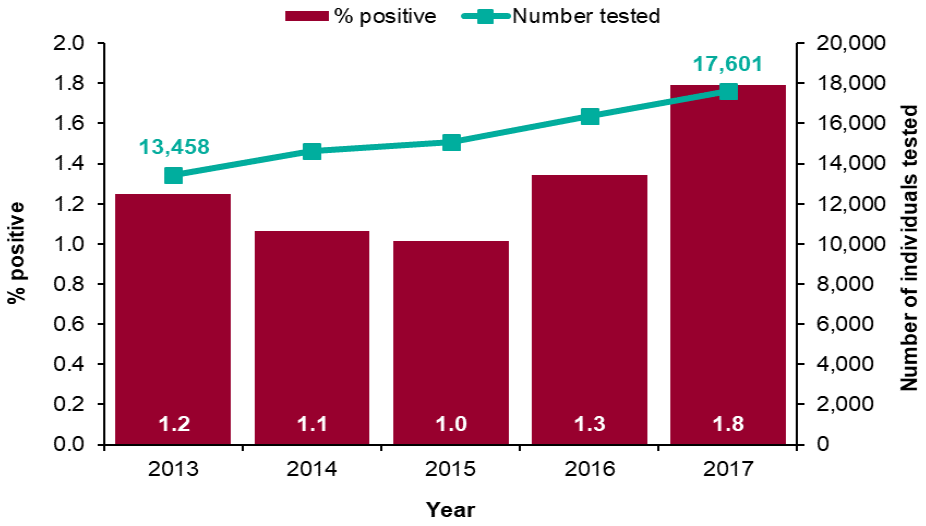
Awareness and reducing undiagnosed infections

Trends in testing as an indicator of increased awareness

Early diagnosis of hepatitis C is important to provide adequate treatment and care and to limit the onward transmission of the virus. With improved drug treatments available, increasing the diagnosis and treatment of HCV through coordinated and sustained awareness-raising activities will contribute to improved clinical and public health outcomes.

Using sentinel surveillance data, it is possible to examine trends in testing over time, which is an indicator of the impact of increased awareness. The number of individuals tested for HCV in the North East has risen steadily between 2013 (13,458 cases) and 2017 (17,601 cases) (Figure 12). The proportion of those tested that had a positive result remained relatively stable around 1% between 2013 and 2015, and has been rising since, with 1.8% of individuals testing positive in 2017. This trend should be interpreted with caution, as the proportion positive might have, to some extent, been influenced by the number of confirmatory tests performed at the North East sentinel laboratory.

Figure 12 – Number of individuals tested and the percentage that tested positive for anti-HCV in sentinel laboratory, North East PHE centre, 2013 to 2017*†

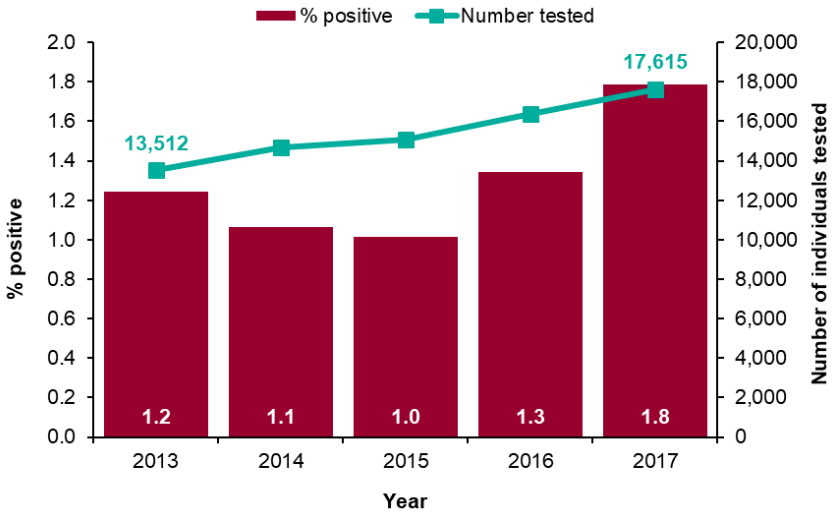


* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Trend data will not necessarily balance back to historic cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

Over the same period, the number of individuals being tested in the North East and Cumbria ODN footprint increased by 31% between 2013 and 2017 (Figure 13). The percentage of positive tests remained relatively stable around 1% between 2013 to 2016, and increased to 1.5% in 2017.

Figure 13 – Number of individuals tested and the percentage that tested positive for anti-HCV in the sentinel laboratory, North East and Cumbria ODN, 2013 to 2017*,†



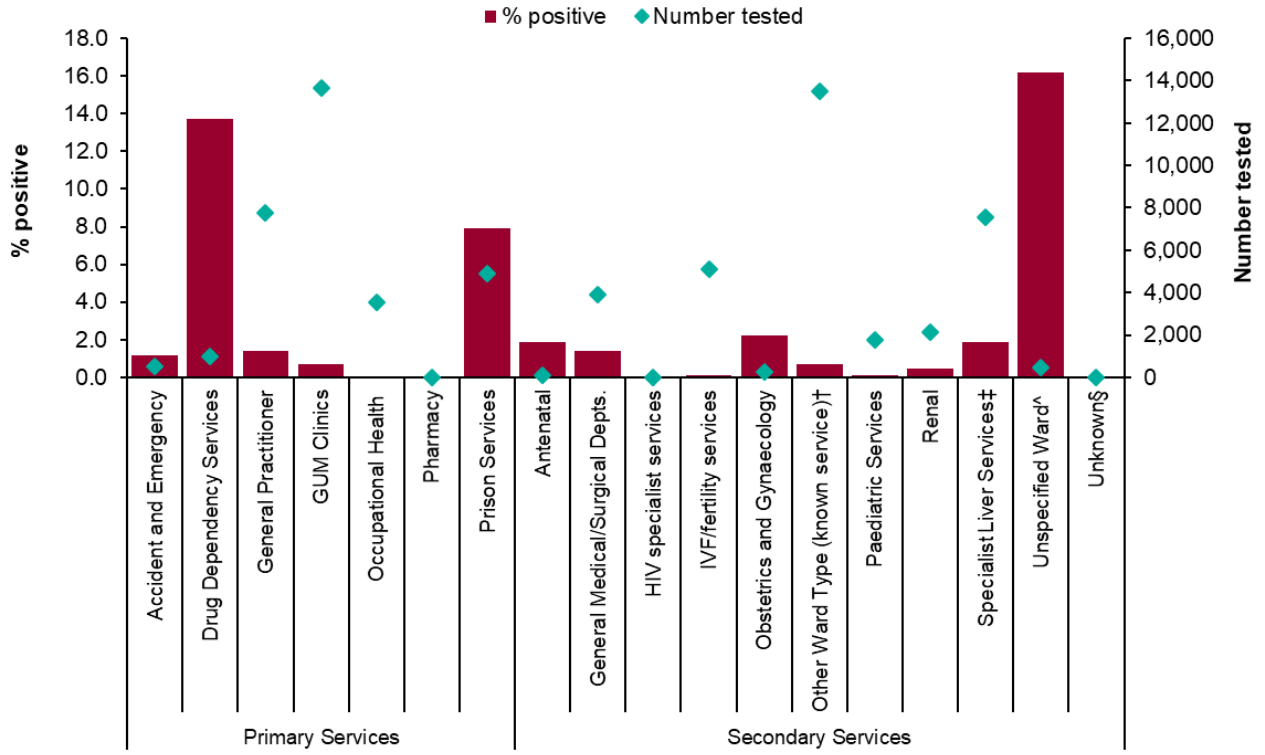
Site of testing

From 2013 to 2017, where service type was specified, the North East sentinel laboratory predominantly received samples from Genitourinary Medicine (GUM) clinics (20.6% of all samples), followed by General Practices and Prison services in the community, and Specialist liver services and Other ward types in the secondary care (Figure 14). Testing appeared to be low in 'unspecified' hospital wards^ and drug dependency services – however, these sites accounted for the highest proportion of positive tests (16.2% and 13.7% respectively). The proportion of positive tests were also high in the prison services (6.7%). There is likely an underestimation of testing at such services as sentinel laboratory data does not include DBS or oral fluid testing, which are more commonly used in these settings. It is important to note that the numbers relate to anti-HCV reactivity testing at the North East sentinel laboratory and may not be representative of all test sites across the North East.

* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

Figure 14 – Number of individuals tested for anti-HCV and the percentage positive by service type in the sentinel laboratory, North East PHE centre, 2013 to 2017*†‡^§



Key findings

The number of people tested for HCV in the North East sentinel laboratory has increased between 2013 and 2017. The proportion of those tested positive remained relatively stable around 1% until 2015, and has risen to 1.8% in 2017 although this should be interpreted with caution, as the proportion positive might have, to some extent, be influenced by the number of confirmatory tests performed at the North East sentinel laboratory

During this period, testing was predominantly carried out at GUM clinics and 'other ward types' (which includes, but does not specify: cardiology, dermatology haematology, ultrasound, and x-ray wards) – however, the proportion of those who tested positive at these sites was low. The highest proportion of positive tests were from drug dependency and unspecified wards, although the number tested at such sites were low. This was likely due to an underestimation of testing activity as sentinel data excludes DBS and oral fluid tests, which are commonly used in such settings.

* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Other ward types include cardiology, dermatology haematology, ultrasound, x-ray

‡ This refers to infectious disease services, hepatology departments and gastroenterology departments.

^These are hospital services which are currently being investigated to identify specific service type, and may include any of the secondary care services mentioned above.

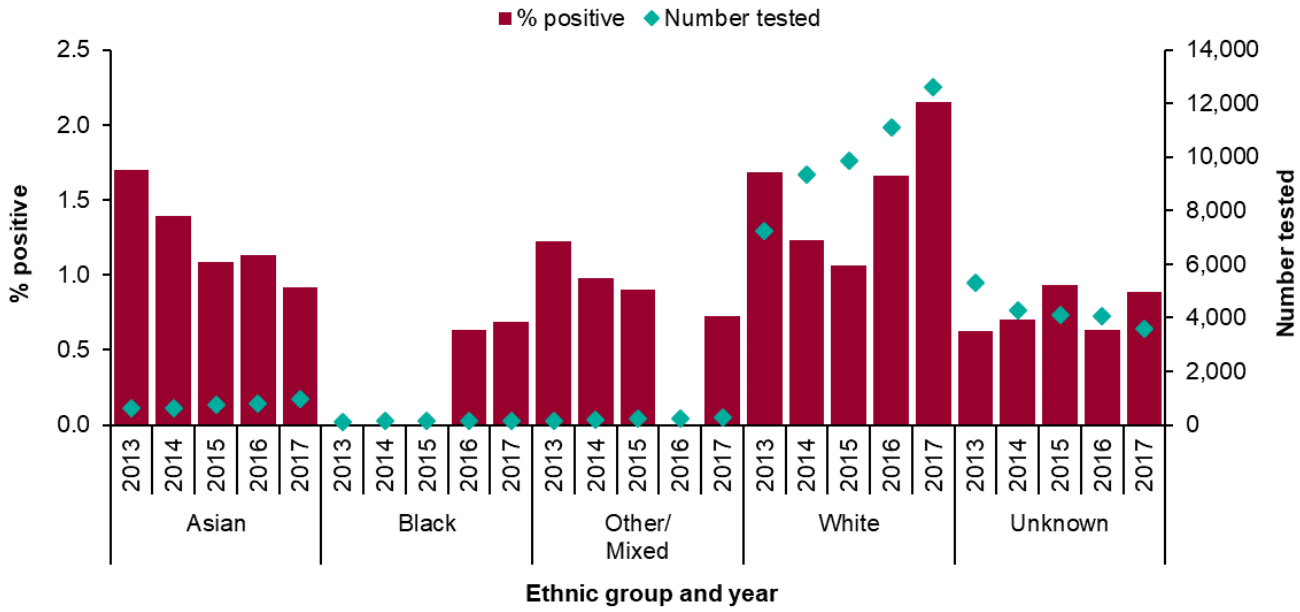
§ These services are currently being investigated to identify specific service type, where possible.

Testing and diagnoses in Black, Asian and minority ethnic populations

The number of people tested and the proportion of those that tested positive at the North East sentinel laboratory was determined by broad ethnic group for the period of 2013 to 2017. Due to a lack of self-reported ethnicity on laboratory forms, ethnicity was predominantly determined using computer software tools (OnoMap and Nam Pehchan).

Tests were predominantly performed in those of white ethnicity, reflecting the overall demographics of the North East, with a low number of tests performed in Black, Asian and minority ethnic groups (Figure 15). Where ethnicity was known, the proportion of those tested who were anti-HCV positive was highest in the White ethnicity group, with 2.2% of those tested having a positive result in 2017, followed by those of Asian ethnicity at 0.9%. The proportion of positive tests was comparable between black and other/mixed ethnicity populations in 2017.

Figure 15 – Number of individuals tested and the percentage that tested positive for anti-HCV by ethnic group in the sentinel laboratory, North East PHE centre, 2013 to 2017*†‡



Between 2013 and 2017, the number of people of Asian or British Asian ethnicity who were tested for HCV in the North East increased from 671 in 2013 to 914 in 2017, potentially due to targeted awareness-raising campaigns in South Asian communities[4]

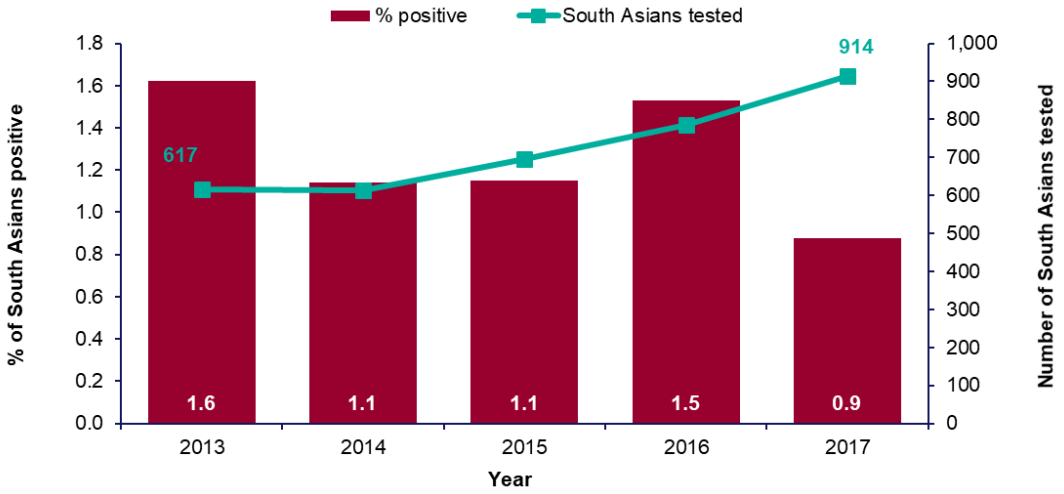
* These sentinel surveillance data exclude dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Trend data will not necessarily balance back to historic cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

‡ A combination of self-reported ethnicity, and OnoMap and NamPehchan name analyses software were used to classify individuals according to broad ethnic group.

(Figure 16) . The proportion of individuals of Asian ethnicity testing positive for anti-HCV fell to 0.9% in 2017. This was the lowest level recorded over the past 5 years (2013 to 2017; average: 1.2%), from a peak of 1.6% in 2013. This was lower compared to national figures (2013 to 2017 average: 1.6%).

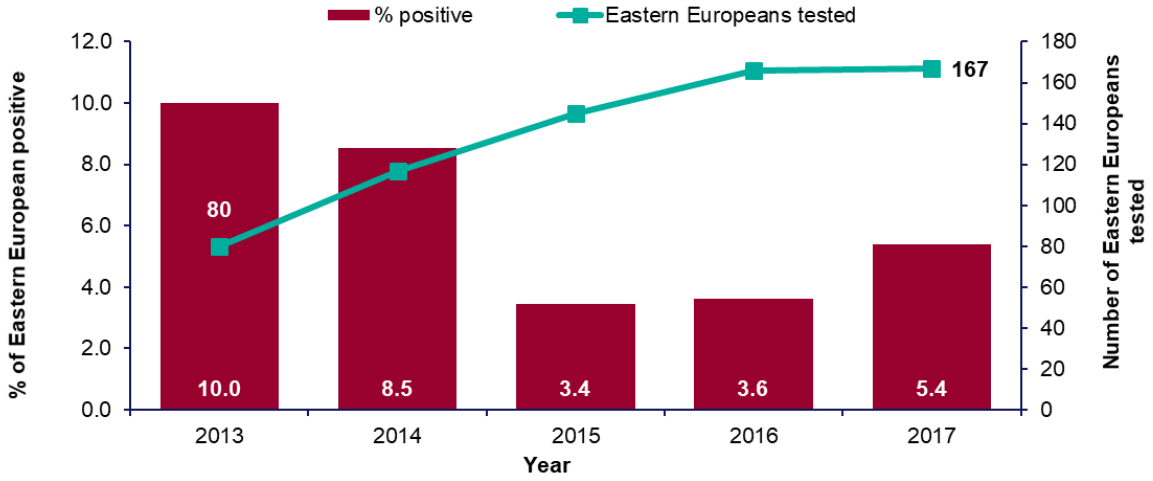
Figure 16 – Number of South Asian individuals tested and testing positive for anti-HCV by ethnicity in the sentinel laboratory, North East PHE centre, 2013 to 2017*†‡



National sentinel surveillance data suggests that individuals of Eastern European origin (self-reported or software derived) may be at increased risk of having hepatitis C or that testing of this ethnic group is more targeted to higher risk individuals, with 5.6% of people of Eastern European origin who were tested for HCV testing positive between 2013 to 2017[1]. In 2017, 5.4% of Eastern Europeans tested in the North East tested positive, which was a decrease from 10.0% in 2013, however the numbers tested were small – 80 in 2013 increasing to 167 in 2017 (Figure 17).

* NamPehchan was used to identify individuals of South Asian origin as ethnicity is not routinely available from the participating laboratory information systems.
† Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.
‡ Trend data will not necessarily balance back to historic cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

Figure 17 – Number of Eastern European individuals tested and testing positive for anti-HCV in the sentinel laboratory, North East PHE centre, 2013 to 2017*†‡



Key findings

According to sentinel surveillance, testing was highest in those of White ethnicity, reflecting the demographics of the North East, with low numbers of tests performed in those of Black, Asian and Other/Mixed ethnicities. By broad ethnic group, the highest proportion of positive tests were also in those of White ethnicity (2.2%). People of Eastern European origin reported 5.4% positivity, although the number of tests performed in this population were very low. Positivity has fluctuated over the period 2013 to 2017 in those of South Asian origin, although it reached its lowest level in 2017 at 0.9%.

Testing and diagnosis among people in secure and detained settings

Prisoners are considered to be at higher risk of infection from blood borne viruses (BBVs), including hepatitis C virus (HCV) when compared to the general population. Risk factors that contribute to this increased risk include homelessness, high-risk behaviour, injecting drugs and unprotected sex with multiple partners. A significant contributor to this increased risk of BBV among prisoners is injecting drug use inside and outside of prison, and the sharing of injecting equipment and paraphernalia[7].

In England, in financial year 2017/18, (using Health and Justice Indicators of Performance preliminary figures) the proportion of new receptions receiving a test within 31 days was 26%[4]. North East data from prison settings were not made available to PHE due to data quality issues at a local level.

* A combination of self-reported ethnicity, and OnoMap and NamPehchan name analyses software were used to classify individuals according to broad ethnic group.
† Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.
‡ Trend data will not necessarily balance back to historic cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

Testing and diagnosis in people who inject drugs (PWID)

People Who Inject Drugs are the group most affected by hepatitis C in England[4]. Of the diagnosed hepatitis C infections in England where exposure data was known, around 90% are thought to have been acquired through injecting drug use[8].

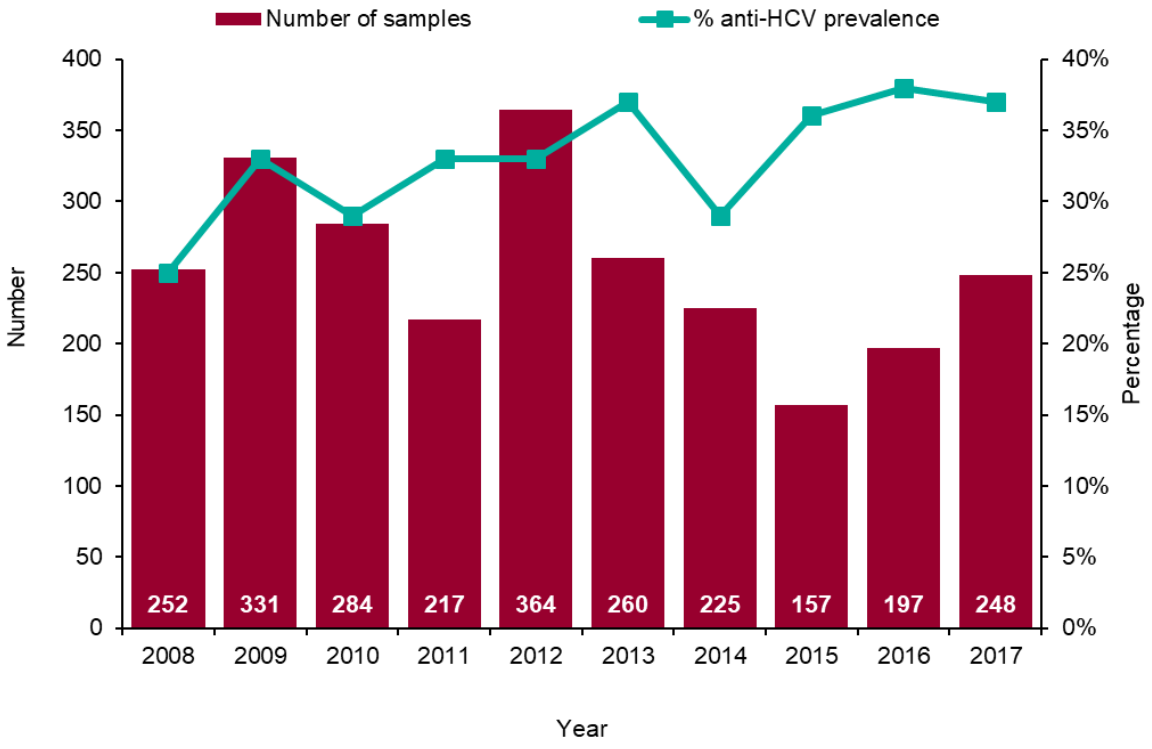
The Unlinked Anonymous Monitoring (UAM) survey of PWID is an annual cross-sectional survey of individuals who currently or previously inject psychoactive drugs who are in contact with specialist services[8]. Those who agree to take part provide a biological specimen that is tested anonymously for HIV, hepatitis C and hepatitis B. Behavioural and limited demographic information is collected through a brief anonymous subject-completed questionnaire linked to the specimen but unlinked from any client identifying information. The type of sample taken started to change from Oral Fluid (OF) to Dry Blood Spot (DBS) in 2009.

It is important to note that the North East data may not be representative of all PWIDs due to the limited number of sites from which this data is taken. This data may also not reflect the prevalence of hepatitis C in PWIDs that are not in contact with health services.

In the North East there has been a gradually increasing trend in anti-HCV prevalence in PWID who participated in the UAM survey, observed since 2008, with 37% of UAM samples positive for anti-HCV in 2017 (Figure 18). This increase has been to some extent attributed to the introduction of Dry Blood Spot (DBS) testing, which is more sensitive than the previously used oral fluid tests. Anti-HCV prevalence in PWID undertaking the UAM survey in the North East was significantly lower than the prevalence in England in 2017 (52%; 95% CI: 50%-54%), with the anti-HCV prevalence also increasing nationally over the past decade[8].

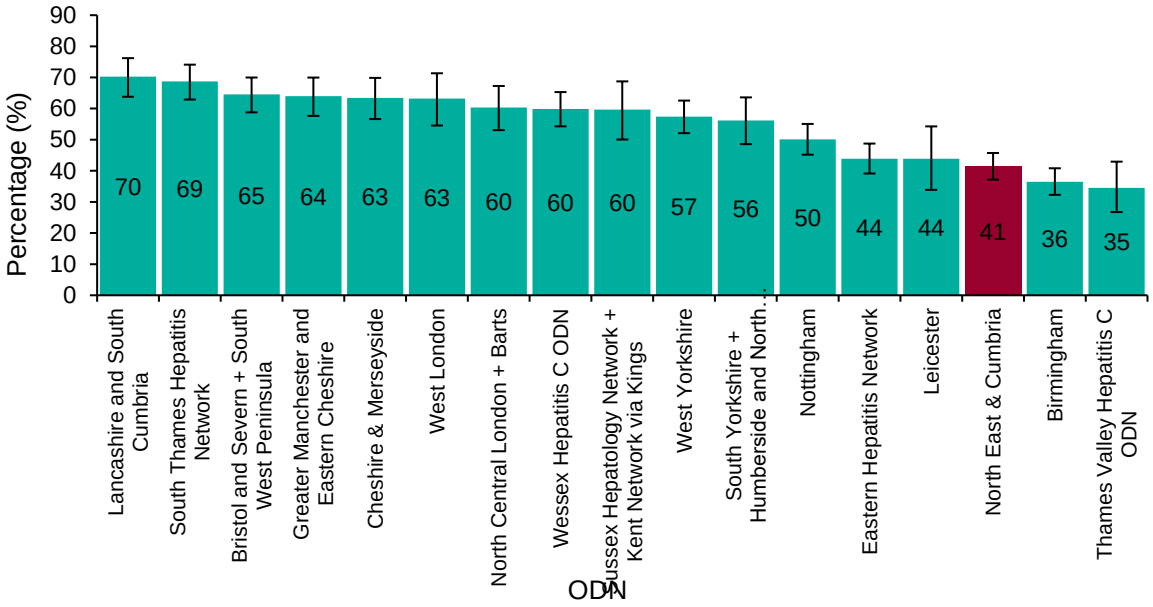
HCV prevalence data from the UAM survey was available by ODN for 2016/17 (Figure 19). Anti-HCV prevalence for the North East and Cumbria ODN was 41.4% (95% CI: 37.2%-45.7%) which was one of the lowest compared with other ODNs in England. Note that differences in HCV prevalence by ODN may be reflective of differences in recruitment for the UAM survey rather than actual differences in HCV prevalence.

Figure 18 – Number of samples and the percentage of anti-HCV prevalence, PWID, North East region, 2008 to 2017* †



Data source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID

Figure 19 – Percentage anti-HCV prevalence in PWID by Operational Delivery Networks, England, 2016/17‡



Data source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID

* The sensitivity of the oral fluid test for anti-HCV is approximately 92%, and that for anti-HBc is approximately 75%.
† Anti-HCV Prevalence = [(number of oral fluids anti-HCV positive/0.92) + number of DBS anti-HCV positive] / (number of oral fluids + number of DBS)x100.
‡ Data are not available for Surrey Hepatitis Services ODN.

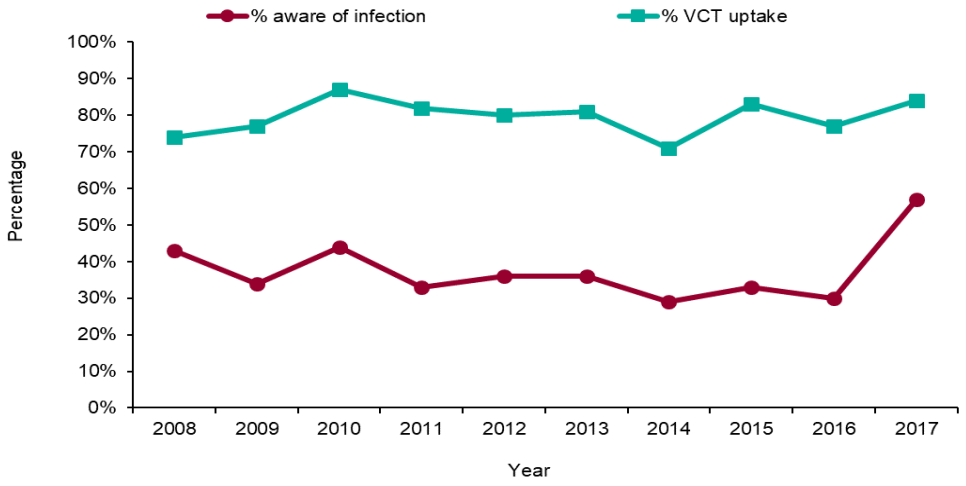
Awareness and HCV voluntary test uptake among PWID

UK clinical guidelines recommend that all PWID accessing treatment services are tested for HCV and HIV at first assessment, and that repeat testing should be considered when the risk of exposure continues. When risk is assessed as high, testing may need to be carried out up to once or twice a year[10]. The proportion of PWID who report uptake of voluntary confidential testing for hepatitis C has increased across the UK in the last decade[8]. While Scotland has seen a sustained increase, England, Wales and Northern Ireland have seen a more gradual increase in testing which has possibly plateaued over the last 7 years[8].

The number of PWID who reported a voluntary confidential test (VCT) in the North East increased from 77% of those answering the question (n=149) in 2016 to 84% of those answering the question in 2017 (n=198; Figure 20). The overall uptake of VCT in PWID who took part in the UAM survey has varied over the past decade, with VCT uptake reported to reach a low of 71% in 2014 and a peak of 87% in 2010. Nationally, self-reported uptake of VCT increased significantly from 74% (95% CI: 73%-76%) in 2007 to 84% (95% CI: 82%-85%) in 2017. The 2017 VCT uptake in the North East was comparable to the figure for England, Wales and Northern Ireland overall.

The proportion of PWID taking part in the UAM survey in the North East that were aware of their HCV infection averaged at around 35% over 2008 to 2016. Awareness of HCV infection increased to 57% in 2017. Despite this increase, awareness was significantly lower compared to awareness among survey participants nationally (66%; 95% CI: 63%-69%).

Figure 20 – Hepatitis C test uptake among PWID and their awareness of infection, North East region, 2008 to 2017*†



Data source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID

* The sensitivity of the oral fluid test for anti-HCV is approximately 92%, and that for anti-HBc is approximately 75%.

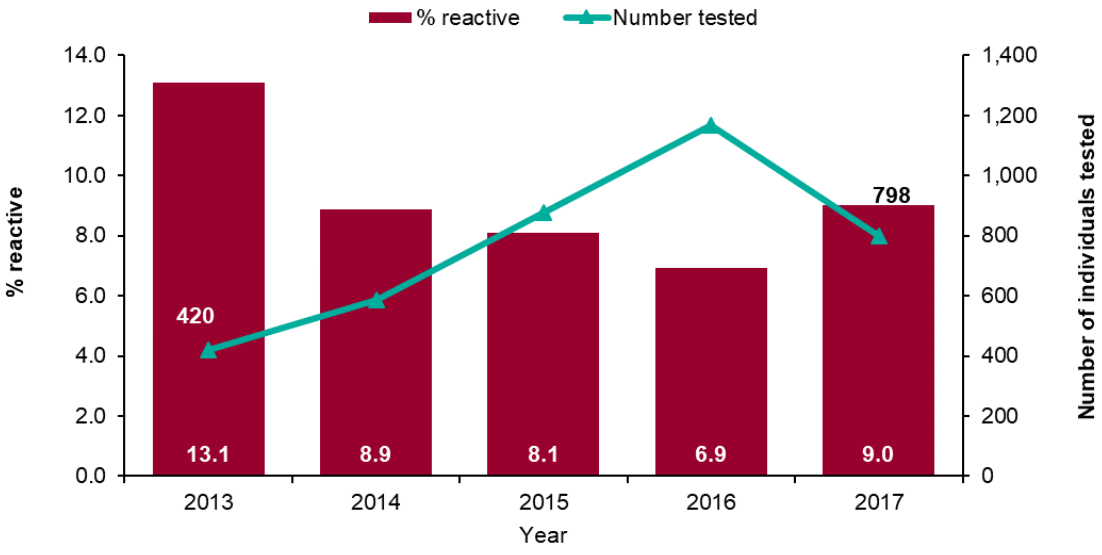
† Due to changes in survey questions regarding awareness of HCV infection status, data from 2017 are not directly comparable to previously collected data.

Offer and uptake of HCV testing at specialist drug services in the North East sentinel laboratory

Within the sentinel dataset (2013 to 2017), 790 individuals reported injecting drugs, of which 21.1% were found to be HCV positive, compared with 1.5% positivity among individuals who did not inject drugs (65,169 tested).

The number of PWID who were referred by specialist drug services for HCV testing showed an increasing trend from 2013 to 2016, however a decrease was observed in 2017 compared to 2016 (798 vs 1,167; Figure 21). The proportion of those tested who were reactive for anti-HCV decreased annually between 2013 and 2016 (13.1% to 6.9%), but increased in 2017 to 9.0%, the highest proportion reported since 2013. These data should be interpreted with caution, as sentinel surveillance may not be representative of regional trends. In particular, DBS tests, which now outweigh venous blood testing in the drug services setting[4], are likely to have been underestimated as sentinel surveillance does not fully capture DBS testing results.

Figure 21 - Number of persons who inject drugs tested and testing positive for anti-HCV at specialist drug services in the sentinel laboratory, North East PHE centre, 2013 to 2017*†‡§



* These sentinel surveillance data exclude reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Only one laboratory offers dried blood spot testing of anti-HCV. These data are presented from 2010 and are shown by PHE centre of the requesting clinician.

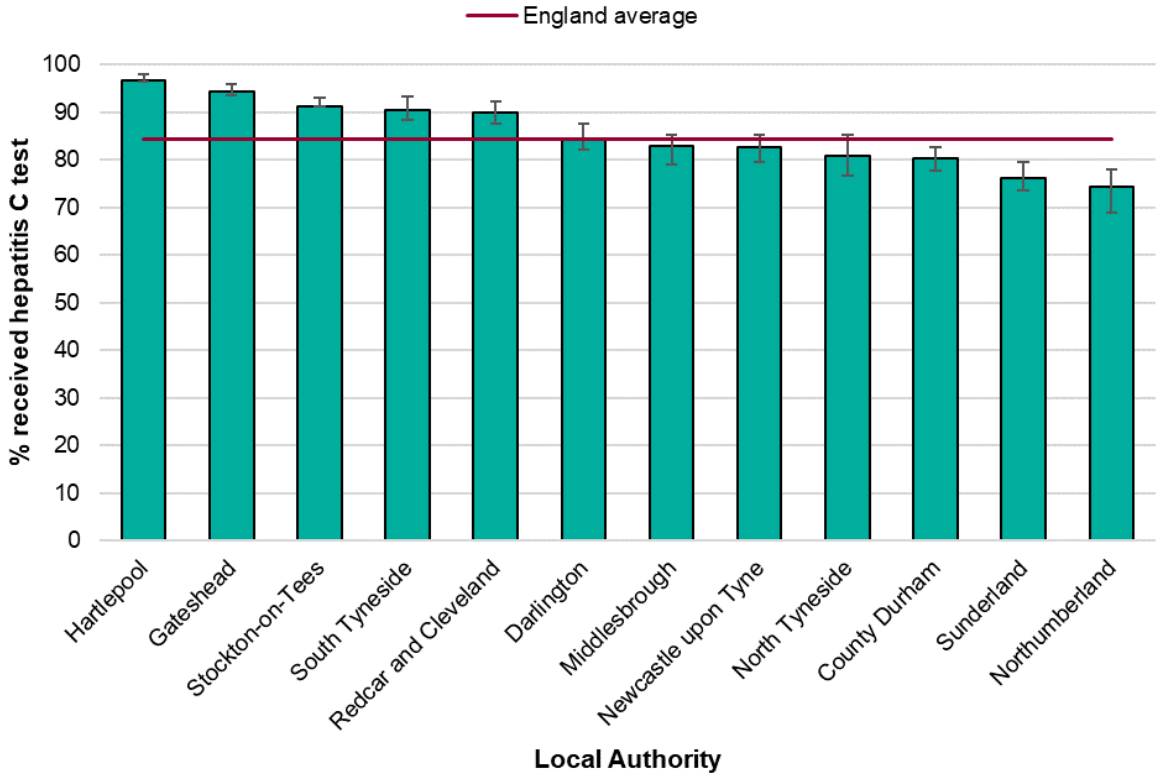
‡ Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

§ Please note: Sentinel surveillance captures a small proportion of all dried blood spot testing in England, therefore these data should be interpreted with caution.

Offer and uptake of HCV testing in current or previous injecting drug users in drug treatment

Data from the National Drug Treatment Monitoring System (NDTMS), available on PHE Fingertips showed that the percentage of eligible persons in substance misuse treatment who received a hepatitis C test was 84.2% (95% CI: 84.0%-84.5%) in England in 2017 and 2018. This was comparable to the North East during the same period (84.7%, CI: 83.9%-85.5%; Figure 22). Uptake of testing in 5 North East local authorities (Hartlepool, Gateshead, Stockton, South Tyneside and Redcar and Cleveland) was significantly higher than the England and North East region average, while testing in 3 local authorities (County Durham, Sunderland and Northumberland) was significantly lower.

Figure 22 - Percentage of eligible persons in substance misuse treatment who inject drugs who have received a hepatitis C test, North East local authorities 2017 and 2018*



Source: PHE Public Health Profiles (Fingertips), based on National Drug Treatment Monitoring System data

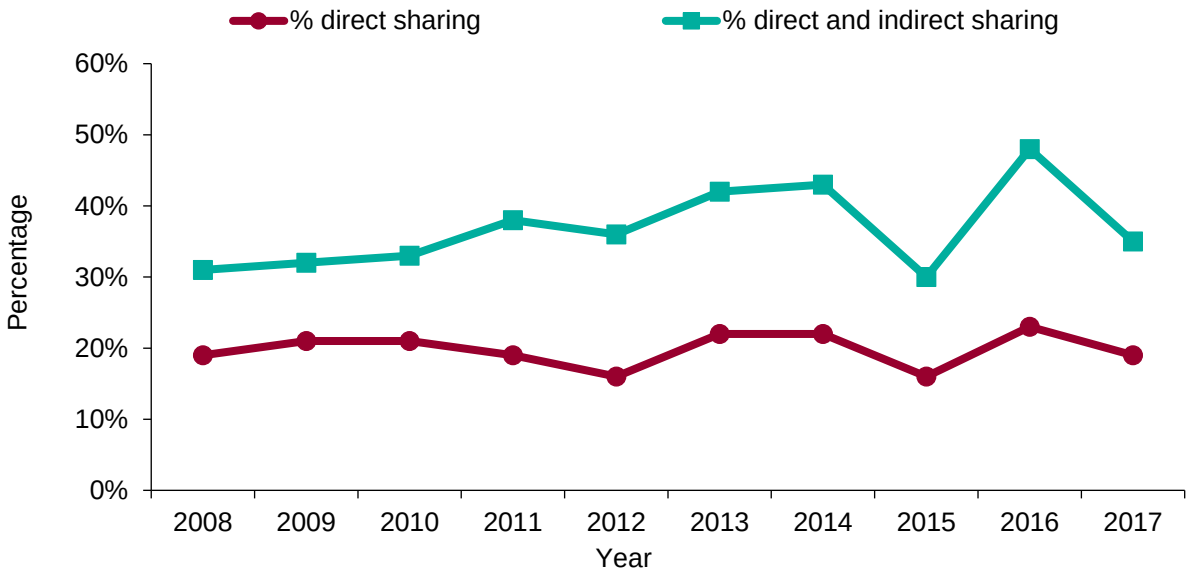
* Percentage of persons in structured drug treatment who currently or have previously injected drugs who received a hepatitis C test. Receipt of a hepatitis C test is determined by the presence of a hepatitis C test date or a flag that the person has been tested for hepatitis C in the current treatment journey in NDTMS. All individuals who currently or previously injected drugs are considered eligible unless they have a hepatitis C intervention status in the current treatment journey of 'assessed as not appropriate to offer'.

Needle and syringe sharing and use of needle and syringe programmes among PWID

Overall, the level of needle and syringe sharing (either receiving or passing on a used needle or syringe) reported by those currently injecting psychoactive drugs has fallen across the UK in the past decade. In England, Wales and Northern Ireland, sharing of needles and syringes ('direct sharing') in the past month fell from 23% of current injectors in 2007 to 18% in 2017. When including the sharing of mixing containers or filters ('indirect sharing') as well as needles and syringes, the proportion of current injectors reporting sharing in the past month was 36% in 2017 in England, Wales and Northern Ireland, which was a decrease from 45% in 2007[8].

In the North East, the proportion of current injectors reporting direct sharing in the past month was 19% in 2017 and the proportion of current injectors reporting direct and indirect sharing in the past month was 35% (Figure 23), which was similar to the 2017 England figures.

Figure 23 - Level of direct* and indirect† sharing of injecting equipment among PWID, North East region, 2008 to 2017



Data source: Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in PWID

Testing and diagnosis of HCV in young adults

In the UK, most new infections are acquired via injecting drug use at a relatively young age. For this reason, the burden of infections in young adults (15 to 24 years) can be used as a proxy measure of incidence.[1] From 2013 to 2017, the number of young adults tested for HCV in the sentinel laboratory in the North East increased by 4.8% (Table 4).

* Sharing of needles and syringes among those who had last injected during the 4 weeks preceding participation in the survey.
† Sharing of needles and syringes, mixing containers, or filters among those who had last injected during the 4 weeks preceding participation in the survey.

Over the same period, the proportion of positive HCV tests in young adults varied from 0.2% to 0.4%, with 0.3% testing positive in 2017, all of whom were aged 20 to 24 years (2017 England average: 0.6%).

The proportion of overall North East laboratory reports attributable to young adults decreased from 5.4% in 2013 to 2.2% in 2017 (Table 4) with the lowest proportion reached in 2014 (3.5%). Although this decline is promising, this may not necessarily correspond to a decline in new infections among young adults. The overall demographics of those tested are likely to have changed over time due to the expansion of testing in more diverse settings, such as prisons and drug services. This may have diminished the impact of this age group on the proportion of positive samples.

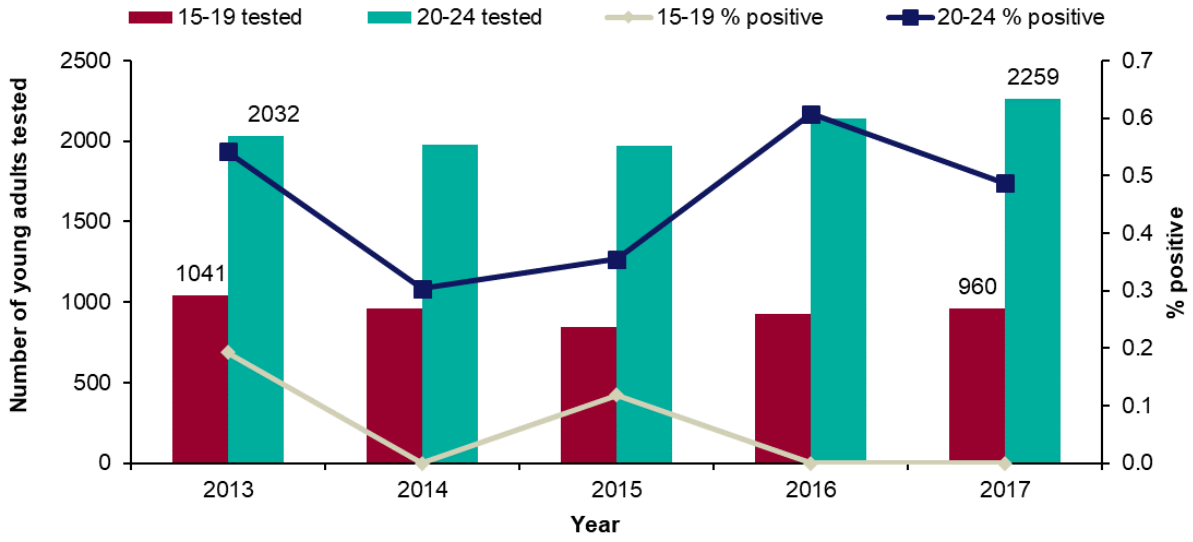
Table 4 – Number and percentage of hepatitis C reports in young adults aged 15 to 24, residents of North East PHE centre, 2013 to 2017*†

Year	Number aged 15-19 years	Number aged 20-24 years	Number aged 15-24 years	% aged 15-19 years	% aged 20- 24 years	% aged 15-24 years
2013	*	18	22	*	4.5	5.4
2014	5	6	11	1.6	1.9	3.5
2015	*	10	12	*	3.4	4.1
2016	*	7	10	*	2.9	4.1
2017	0	8	8	0.0	2.2	2.2
Total	**14**	**49**	**63**	**0.9%**	**3.0**	**3.9**

Counts below 5 have been suppressed (*)

* Data are summarised by PHE centre of residence, not PHE centre of laboratory. Data are assigned to PHE centre by patient postcode where present – if patient postcode is unknown, data are assigned to PHE centre of registered GP practice, where both patient postcode and registered GP practice are unknown data are assigned to PHE centre of laboratory.
† Includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA. Due to the variability in the quality of laboratory reports and the inability of current serological assays to differentiate acute from persistent infections we are unable to estimate the actual proportion of cases with evidence of past infection or persistent infection.

Figure 24 – Number of young adults tested and percentage testing positive for anti-HCV in the sentinel laboratory, North East PHE centre, 2013 to 2017*



Key findings

There has been an increasing trend in anti-HCV prevalence in PWID who responded the UAM survey in the North East since 2008, with 37% of UAM samples positive for anti-HCV in 2017. This increase was to some extent attributed to the introduction of DBS testing, which is more sensitive than the previously used oral fluid tests.

Data from sentinel surveillance suggests that the number of drug users referred by specialist drug services for HCV testing has decreased in 2017, while the proportion testing positive has increased. These data should be interpreted with caution, as sentinel surveillance may not be representative as it does not fully capture DBS testing in the region.

The proportion of PWID sharing injecting equipment has decreased over the past decade nationally, however, North East data suggests that the regional trend over this period has remained stable. Self-reported testing uptake increased both in the North East and nationally in 2017, with uptake in the North East comparable to the figures for England, Wales and Northern Ireland overall. In accordance with this, the proportion of survey participants aware of their hepatitis C status in the North East has also increased, although the figure was significantly lower than that seen nationally.

* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional. Trend data will not necessarily balance back to cumulative data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

HCV test uptake of eligible people in substance misuse treatment reported in 5 North East local authorities (Stockton-On-Tees, Gateshead, Redcar and Cleveland, Hartlepool and South Tyneside) was significantly higher than the England and North East region average, while uptake in a further 3 local authorities in the region was significantly lower than the national and regional averages.

The proportion of young adults (aged 15 to 24 years) testing positive for HCV, a proxy measure of HCV incidence, has shown a general decrease in trend since 2012. However, these figures should be treated with caution as demographic changes in the population being tested may have diminished the impact of this age group in the proportion of positive samples.

Monitoring the coverage of key services

The prevention of new infections requires adequate harm reduction approaches to be in place. The following section details the main risk factors associated with the acquisition of HCV in patients diagnosed in the North East, and harm reduction strategies in place in the region to prevent new infections and onward transmission.

Risk factors associated with HCV infection in the North East

Of those testing positive in the North East sentinel laboratory between 2013 and 2017, risk exposure information or the reason for testing was known in 74.8% of cases. Where specified, the biggest risk exposure/reason for testing was screening (24.1%) and PWID (17.4%) among positive cases. Other common reasons for testing included liver disease symptoms (11.1%) and confirmatory testing (8.4%) (Table 5).

Table 5 – Risk exposures for individuals tested for anti-HCV in the sentinel laboratory, NE PHE centre, 2013 to 2017*†‡

Risk exposure/reason for testing	Number tested	Number positive	% testing positive	% of all positive cases
Antenatal screening	1,459	15	1.0	1.3
Confirmatory test	850	96	11.3	8.4
Contact testing	183	10	5.5	0.9
Fertility treatment screening	856	*	*	*
LFTs - abnormal result	5,114	30	0.6	2.6
Liver disease symptoms	2,988	126	4.2	11.1
Maternal/vertical exposure	117	*	*	*
Needlestick donor/recipient	1,733	6	0.3	0.5
Other medical condition	1,268	*	*	*
PWID	880	198	22.5	17.4
Renal patient	1,898	11	0.6	1.0
Risk of infection	1,270	38	3.0	3.3
Screening	30,500	274	0.9	24.1
Sexual exposure	1,313	16	1.2	1.4
Study participants	100	0	0.0	0.0
Symptoms (non-liver)	2,254	17	0.8	1.5
Travel or lived abroad	701	9	1.3	0.8
Unknown	12,786	287	2.2	25.2
Total	66,270	1,137	1.7	100.0

Counts below 5 have been suppressed (*)

* Excludes dried blood spot, oral fluid, reference testing and testing from hospitals referring all samples. Data are de-duplicated subject to availability of date of birth, soundex and first initial. Excludes individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection. All data are provisional.

† Please note: clinical details on risk factors and/or reasons for testing were only available for a small proportion of individuals and these data should be interpreted with caution.

‡ Cumulative data will not necessarily balance back to historical trend data because only locations that have been consistently reported in each of the 5 years can be included in trend data.

While risk exposure information was relatively complete in the sentinel dataset, most likely route of infection was less well recorded in laboratory reports overall. Only 9% (32/365) of all laboratory notifications in 2017 were given an associated route of infection, with injecting drug use the most likely route of infection reported (81%).

Key findings

In the North East sentinel laboratory dataset between 2013 and 2017, the risk exposure information or the reason for testing was known in 74.8% of cases. Where specified, the biggest risk exposure/reason for testing was screening (24%) and injecting drug use (17%).

Local Initiatives

The North East and Cumbria Hepatitis C Operational Delivery Network (NEC ODN) is working towards improving hepatitis C treatment pathways through enhanced testing of those at risk of HCV and management of treatment decisions and prescribing. Newcastle-upon-Tyne Hospitals NHS Foundation Trust hosts the NEC ODN, and is supported by 7 other NHS Trusts across the area, in addition to other stakeholders such as drug and alcohol services.

Improved testing and treatment in prisons

Following the introduction of opt-out BBV testing in the region's prisons, specialist nurse in-reach weekly clinics and consultant-led telemedicine clinics have been rolled-out across all North East Prisons to streamline the treatment pathway and reduce the number of out of prison consultations required. This has increased the uptake of treatment among this key risk group.

Increasing awareness through outreach

Outreach clinics have been embedded in drug treatment centres, needle exchanges and GP surgeries throughout the region. New locations such as community pharmacies are being piloted to assess the evidence that expansion into these settings could further widen the cohort of patients reached by awareness messages and improve equity of access.

The NEC ODN is working closely with the Hepatitis C Trust on a peer support programme that delivers education sessions and supports outreach. The programme is looking to expand its peer support capacity and include patient representation to ensure a patient centred model of care delivery. Its aims are to increase HCV awareness, maximise the number of individuals being tested, and support those diagnosed with HCV to access and complete the treatment process.

Hard to reach patients

In local authorities where HCV treatment services have been unavailable at the local referral hospital, nurse-led clinics in the community were established by the region's host Trust to reduce the burden of travel for patients. Work on establishing further clinics is planned.

Mapping of untreated HCV patients in North East to help direct strategic targeting of treatment services and engagement. A database of untreated individuals has been supplied to NEC ODN for re-engagement efforts. Work to contact these individuals for treatment referral is being undertaken by the NEC ODN and is currently ongoing.

Conclusions

Despite progress in decreasing the burden and impact of hepatitis C infections, HCV remains an important public health issue both within the North East and nationally.

Laboratory reporting of hepatitis C has increased in the North East in 2017 compared to the previous year although rates of reporting remained low, with 6 North East local authorities showing a rate significantly lower than that for England overall in 2017. The number of people tested for HCV in the North East sentinel laboratory has also been increasing and the proportion of those tested positive has risen to 1.8% in 2017.

Progress has been made in improving the outcomes of people diagnosed with HCV in the North East. The North East was among the lowest nationally for reported deaths from HCV and the number of people with HCV registering for transplant has halved between 2010 and 2013 and 2014 and 2017. The reflection of this trend at the national level suggests that earlier detection and improved treatments have reduced the number of individuals going on to develop serious disease.

The work of the NEC ODN in expanding testing and treatment is clearly having an impact, given the increasing trend in the numbers being tested, and the increased diversity of test settings. With the increasing availability of DAAs and increasing number of HCV-infected individuals now accessing treatment, the North East is making progress in achieving WHO GHSS goals to reduce HCV-related morbidity and mortality,

Hepatitis C continues to disproportionally affect vulnerable and marginalised groups such as prisoners and PWID, with the highest proportion of positive tests in the region coming from drug dependency and prison services. While progress has been made with testing in prisons and specialist drug services, self-reported HCV testing uptake in PWID has not changed substantially over the last decade and many people continue to be at risk of infection through unsafe injecting behaviours. Further work is needed to continue awareness raising and harm reduction strategies and to encourage testing uptake in a wide range of settings.

Recommendations

In the following section evidence-based recommendations are provided in order to continue the progress currently being made in the North East and to address any gaps in service provision with the aim of further reducing the burden and impact of HCV.

Reducing the number of people becoming infected

The number of people testing positive in the North East overall has remained relatively stable since 2012. Raising public awareness remains an important component of reducing the burden of HCV infection. Engagement of the third sector, for example charities such as the Hepatitis C Trust, is useful in accessing groups at high risk of infection through peer support and should continue to be a key aspect of outreach.

The level of needle and syringe sharing among those currently injecting psychoactive drugs has fallen across the UK but there has been a gradual increase in the proportion of PWID who reported sharing of injecting equipment in the North East. It is vital that a broad range of harm reduction and specialist treatment services is made available in diverse settings. Interventions encouraging reduction or cessation of injection as a route of consumption, in combination with adequate injecting-related equipment provision should be sustained to reduce the needle sharing.

Increasing the number of people diagnosed

As well as increasing public awareness, it is important to maintain and improve awareness among health professionals. All stakeholders should continue to improve awareness among health professionals in contact with HCV patients and should receive regular updates on regional testing and treatment strategies.

There has been a slight decrease in voluntary hepatitis C testing in PWID in the North East. Stigma and discrimination are thought to be key drivers that influence declining the offer of a test[8], highlighting the importance of expanding awareness among this group.

Increasing the number of those diagnosed who access treatment

Those responsible for commissioning HCV treatment services should continue to work with all stakeholders to ensure equitable access to treatment, and to increase access to direct-acting antiviral agents (DAA). One of the biggest identified obstacles to treatment access for HCV is the lack of treatment settings suitable for PWID. Multidisciplinary and peer-supported programmes should continue to be expanded and testing should be encouraged in diverse settings to enable rapid referral to a treatment pathway.

Data sources

Burden

Reducing the burden of infection in England

Data set	Data source	Description of dataset
Lab reported infections by PHE centre Lab reports by upper tier local authority: number and rate Lab reports by upper tier local authority: DSR Lab reports by laboratory Lab reports by age group and gender	Laboratory surveillance (EpiNorth3/ SGSS)	Quantifying burden of laboratory-confirmed disease – overall and in specific groups/locations
Sentinel surveillance: HCV by PHE centre and ODN Sentinel surveillance: HCV by age group and gender Sentinel surveillance: HCV PWID Status	Immunisation, Hepatitis and Blood Safety Department, National Infection Service	Describe trend in testing and distribution of risk factors/exposures
PWID Prevalence	Unlinked Anonymous Monitoring Survey of PWID in contact with specialist services	Current burden of disease in a key at-risk population, secular trends, levels of protective and risky behaviour

Impact

Reducing HCV-related morbidity and mortality

Data set	Data source	Description of dataset
Hospital admissions by PHE centre (2013 to 2016)	Hospital Episode Statistics (HES), NHS Digital	Burden of disease (more severe end of the spectrum) and complications
Deaths by PHE centre	ONS mortality	Outcome information used to quantify the impact of disease including premature death and inequities
Transplants by PHE centre	NHS Blood and Transplant Registry	Burden of disease (more severe end of the spectrum) and complications

Reducing the number of new (incident) infections

Lab reports by young adults	Laboratory surveillance (EpiNorth3/ SGSS)	Quantifying burden of laboratory-confirmed disease – overall and in specific groups/locations
Sentinel surveillance: HCV testing of young adults	Immunisation, Hepatitis and Blood Safety Department, NIS	Describe trend in testing and distribution of risk factors/exposures

Service coverage

Adequate harm reduction

Data set	Data source	Description of dataset
Sentinel surveillance: HCV testing in drug services	Immunisation, Hepatitis and Blood Safety Department, NIS	Describe trend in testing and distribution of risk factors/exposures
Sharing of needles among PWID	Unlinked Anonymous Monitoring Survey of PWID in contact with specialist services	Current burden of disease in a key at-risk population, secular trends, levels of protective and risky behaviour

Increasing awareness and the numbers and proportion diagnosed

Sentinel surveillance: HCV testing of South Asian population Sentinel surveillance: HCV testing of Eastern European population Sentinel surveillance: HCV testing by ethnic group Sentinel surveillance: HCV Risk exposures Sentinel surveillance: HCV trends in testing Sentinel surveillance: HCV testing by service type Sentinel surveillance: HCV trends in testing by ODN Sentinel surveillance: HCV testing cumulative % positive by ODN	Immunisation, Hepatitis and Blood Safety Department, National Infection Service	Describe trend in testing and distribution of risk factors/exposures
Blood Borne virus opt-out programme	NHS North of England commissioning support unit	Describe trends in BBV testing within the prison population
HCV infection among new and repeat blood donors	NHS Blood and Transplant monitoring	Seropositivity in the general population
HCV test uptake among PWID	Unlinked Anonymous Monitoring Survey of PWID in contact with specialist services	Current burden of disease in a key at-risk population, secular trends, levels of protective and risky behaviour
Offer and uptake of HCV testing in adults currently or previously injecting	PHE Fingertips	Proportion of eligible drug treatment service clients (previous or current injectors) who received a HCV test

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